Facing Forward Series

Life After Cancer Treatment

U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute

The National Cancer Institute (NCI) is the lead Federal agency for cancer research. Since Congress passed the National Cancer Act in 1971, NCI has continued to collaborate with top researchers and medical facilities across the country to conduct innovative research leading to progress in cancer prevention, detection, diagnosis, and treatment. These efforts have resulted in a recent decrease in the overall cancer death rate and have helped improve and extend the lives of millions of Americans.

In 1996, NCI established the Office of Cancer Survivorship in recognition of the increasing number of people surviving cancer and their unique needs. Over the last decade, NCI has supported research by a growing number of doctors and scientists committed to understanding the needs of people with cancer. We have learned a great deal about the experience of cancer survivors, and we want to share our findings with you.

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 will tell you what we have learned from other survivors about life after cancer. We will share with you their reactions to recovery; practical tips for dealing with common problems faced after treatment, such as pain, fatigue, and fear that cancer will come back; and guidelines for managing your physical, social, and emotional health after cancer. 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 an opportunity for growth. As difficult as treatment is, thousands of cancer survivors have told us that the experience led them to make important changes in their lives. From simply taking time to appreciate each new day to learning to take better care of themselves—or learning to value how others care for them—to becoming national advocates for better cancer research, treatment, and care, they were affected in the way they felt about themselves, others, and the future. We hope that this booklet will serve as a resource and inspiration to you as you face forward to your life after cancer.

Acknowledgments

The National Cancer Institute thanks the many cancer survivors, scientists, and health professionals who assisted with the development and review of this publication.

This book is also available in Spanish.
Este folleto también se puede obtener en español.

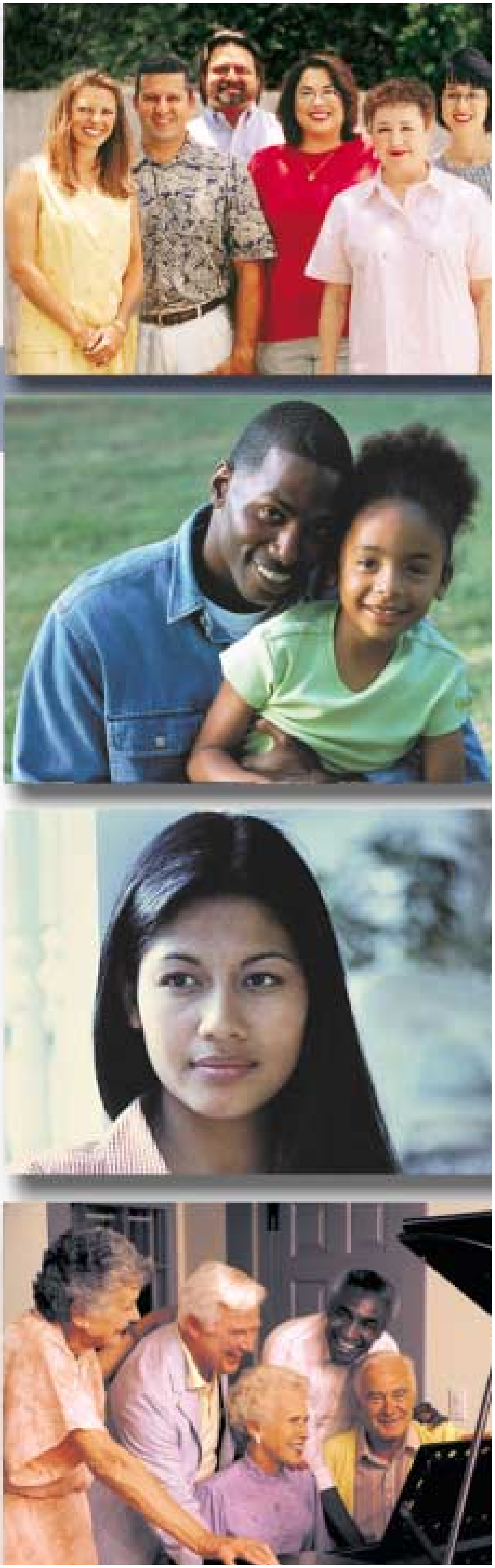
Call **1-800-4-CANCER** for cancer information.

Facing Forward

Life After Cancer Treatment

A Guide for People Who Were Treated for Cancer

This booklet is given to you by



Contents

Introduction i

Getting Medical Care After Cancer Treatment 1
- What Is Follow-up Care? 3
  - Which Doctor Should I See Now? How Often? 4
- Developing a Wellness Plan 6
- Do You Have Trouble Talking With Your Doctor? 8
- Complementary and Alternative Medicine 10
- Services to Think About 14

Your Body After Cancer Treatment 19
- Fatigue 20
- Pain 22
- Lymphedema: Arm or Leg Swelling 28
- Problems With Your Mouth or Teeth 30
- Weight Changes 33
- Bowel and Bladder Control 36
- Menopause Symptoms 37
- Intimacy and Sexuality 40
- What if I Have Other Health Problems? 44

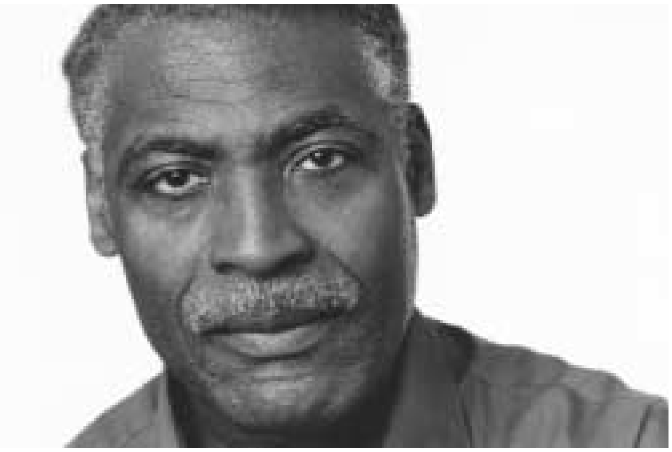
Your Mind and Your Feelings After Cancer Treatment 47
- Fear That Cancer Will Come Back 48
- Feeling Stress 52
- Dealing With Depression and Anxiety 53
  - Getting Help for Depression 53
- Dealing With Changes in Memory and Concentration 55
- Dealing With Body Changes 57
- Feeling Angry 59
- Feeling Alone 59
- Joining a Support Group 61
  - Types of Support Groups and Where to Find Them 62
  - Is a Support Group Right for You? 62
- Finding Meaning After Cancer Treatment 64
  - Finding Meaning Through Faith, Religion, or Spirituality 67

Your Social Relationships After Cancer Treatment 71
Issues With Your Family 71
Getting Help With Family Issues 74
Issues With Partners and Dating 75
Getting Help With Partner and Dating Issues 76
Issues at Your Workplace 78
Issues With Friends and Coworkers 80
Getting Help With Issues Involving Friends and Coworkers 81

Dealing With Practical Matters After Cancer Treatment 85
General Cancer Resources 86
Employment and Legal Rights 89
Health Insurance Concerns 92
Help With Medical Costs 94
Resources for Specific Groups 99
Other Resources by Topic 102
Additional Resources 104

Glossary 108
Organization Guidelines for Follow-up Care 110
Cancer Survivors' "Bill of Rights" 111
Patient Notes/Follow-up Care Guide 115
Pain Diary 120
Practicing Relaxation to Relieve Pain or Stress 121

Introduction



"While I was having chemo I just quit doing most anything … so, the challenge for me was, what am I going to do now with my life? What should I go back to doing?"

Len, colon cancer survivor, 60

What Is "Normal" After Cancer Treatment?

Congratulations on Finishing Your Cancer Treatment!

Ending cancer treatment can be both exciting and challenging. Most people are relieved to be finished with the demands of treatment, but many also feel sadness and worry. Many are concerned about whether the cancer will come back and what they should do after treatment.

When treatment ends, people often expect life to return to the way it was before they were diagnosed with cancer. This rarely happens. You may have permanent scars on your body, or you may not be able to do some things you once did easily. Others may think of you—or you may view yourself—as being somehow different.

One of the hardest things after treatment is not knowing what happens next. *"Because the doctors and nurses never told me the range of what to expect, I had expectations of wellness that were absolutely unrealistic,"* one woman said, *"and so did my family and friends. This . . . led to a great deal of worry."*

What is "normal" after cancer treatment? Those who have lived through treatment talk about the first few months as a time of change. It is not so much "getting back to normal" as it is finding out what is normal for you now. You can also expect things to keep changing as you begin your recovery. As one man put it, *"I thought when I had finished treatment—when they looked at my tests and they said it looked good—I thought, 'OK, this is done'. . . [but] it is not over."*

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

How to Use This Booklet

The information in this booklet is designed mainly for cancer survivors who have recently completed their cancer treatment, but you may find the information helpful even if you were treated a long time ago. The purpose of this booklet is to give cancer survivors and their loved ones a better idea of what to expect during the first few months after treatment ends. Its five main sections cover what may happen with:

- Your medical care
- Your body
- Your mind and your feelings
- Your social relationships
- Practical matters such as job and insurance issues

Do not feel you have to read the whole booklet at once. It is meant for you to use over time. Flip through to see what may be helpful to you, or check out topics as they come up in your life.

As you'll see, this booklet talks about many concerns of those who have been through cancer treatment and offers suggestions that have helped others move forward. As you read, you may find yourself saying, *"That's just how I feel."*

Although this booklet describes issues that are important to many survivors, each person has a unique response to having cancer. While some of the issues covered in this booklet may reflect your experience well, other issues may not concern you. Focus on finding what works for you. The information in this booklet is not intended to be all-inclusive. Resources are provided if you need more information on a given topic or one that is not included. We encourage you to be active in getting the information and support you need.

We use two symbols to help you find your way through the information in the booklet:

means that this section discusses medical approaches to addressing this problem.

✓ means that this section has helpful hints that have helped other survivors cope with this problem.

Keep in Mind

In this booklet, the term *cancer survivor* is used to include anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life. 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.

Getting Medical Care After Cancer Treatment

Getting Medical Care After Cancer Treatment

"You have to be in control—your body talks to you—and you've got to use the doctor as a consultant. You've got to find out what is wrong, because it is your life."

Mae, uterine cancer survivor, 54

"I didn't know what to ask. So I asked my doctor what I needed to know."

Jack, bladder cancer survivor, 70

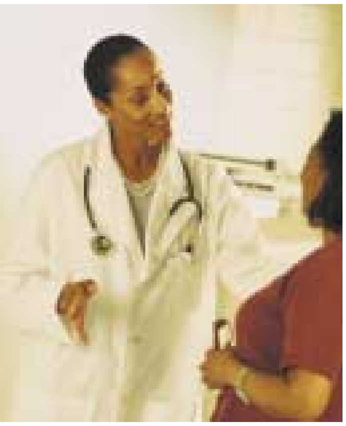
It is natural for anyone who has finished cancer treatment to be concerned about what the future holds. Many people worry about the way they look and feel and about whether the cancer will come back. Others wonder what they can do to keep cancer from coming back. Understanding what to expect after cancer treatment can help survivors and their families plan for follow-up care, make lifestyle changes, stay hopeful, and make important decisions.

All cancer survivors should have follow-up care. But you may have a lot of questions about getting the care you need now, such as:

- Whether to tell the doctor about symptoms that worry you
- Which doctors to see after treatment
- How often to see the doctor
- What specific tests you need
- What you can do to relieve pain and other problems after treatment
- How long it will take for you to recover from treatment and feel more like yourself

Dealing with these issues can be a challenge. Yet many say that getting involved in decisions about their future 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.

This section offers some guidance on working with the people who provide care after treatment. It describes the kinds of help you may need and provides tips for getting what you want out of your medical visits. Reading this section can also help you create a plan of action for your recovery and future health.



What Is Follow-up Care?

The main purpose of follow-up care is to check if your cancer has returned (recurrence) or if it has spread to another part of your body (metastasis). Follow-up care can also help in:

- Finding other types of cancer
- Spotting side effects from treatment now or that can develop years after treatment

Follow-up care means seeing a doctor to get regular medical checkups. At these visits, your doctor will:

- Review your medical history
- Examine your body

Your doctor may run follow-up tests:

- Imaging procedures (ways of producing pictures of areas inside the body)
- Endoscopy (the use of a thin, lighted tube to examine organs inside the body)
- Blood tests

Follow-up care can also include home care, occupational or vocational therapy, pain management, physical therapy, and support groups. (See pages 14-16 for a description of these services.)

Keep in Mind

If you do not have health insurance, Medicare, or Medicaid, you may feel that some of the information in this booklet will not be helpful to you. You may have already struggled just to get treated and now see getting follow-up care as another battle. It can be hard to get health care if you don't have good health insurance, but you must make sure you get the care you need—especially after 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 government and nonprofit organizations listed in the resource section of this booklet (pages 92-98) that may be able to help with health costs.

Which Doctor Should I See Now? How Often?

You will need to decide which doctor will provide your cancer follow-up care and which one(s) will provide other medical care. For follow-up cancer care, this may be the same doctor who provided your cancer treatment. For other medical care, you can continue to see your family doctor or medical specialist as needed.

Depending on where you live, it may make more sense to get cancer follow-up care from your family doctor than to travel long distances to see an oncologist. No matter whom you choose as a doctor, try to find doctors you feel comfortable with.

At your first follow-up visit, ask your doctor to recommend a follow-up schedule. In general, people who have been treated for cancer 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 for follow-up appointments. Some medical organizations also have follow-up guidelines for certain cancers and update this information as researchers develop new approaches to follow-up care. (See page 110 for contact information.)

Use the Patient Notes/ Follow-up Care Guide on page 115 to keep track of your appointments.

Follow-up care will be different for each person who has been treated for cancer, depending on the type of cancer and treatment he or she had and the person's general health. Researchers are still learning about the best approaches to follow-up care. This is why it is important that your doctor help determine what follow-up care plan is right for you.

Lastly, it is important to note that some insurance plans pay for follow-up care only with certain doctors and for a set number of visits. In planning your follow-up care schedule, you may want to check your health insurance plan to see what restrictions, if any, apply to your follow-up care after cancer treatment.

Keep in Mind

Some people may suspect that their cancer has returned, or they notice other changes in their bodies. It is important for you to be aware of any changes in your health and report any problems to your doctor. Your doctor can find out whether these problems are related to the cancer, the treatment you had, or another health problem.

Even if you learn that your cancer has returned, there is no reason to lose hope. Many people live good lives for many years with cancer that has returned.

Developing a 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 also find that this is a time when they take a good look at how they take care of themselves and their health. This is an important start to living a healthy life after cancer.

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. You may not be used to talking with your doctor as a partner in planning for your health, so it may be hard for you at first, but it is very important that you do it. The more you do it, the easier it will become. For tips on how to talk to your doctor, see page 8.

Research is just beginning to show what people can do to lower their risk of getting certain cancers. But we don't yet know why cancer comes back in some people and not others.

Making changes in the way you eat, exercise, and live your life may not prevent your cancer from coming back. However, making these changes can help you feel better and may also lower your chances of developing other health problems.

Changes you may want to think about:

- **Quitting smoking.** Research shows that smoking can increase the chances of developing cancer at the same site or another site. For help in quitting smoking, see page 16 for Smoking Cessation Programs.
- **Cutting down on how much alcohol you drink.** Research shows that drinking alcohol can increase your chances of developing certain cancers.
- **Eating well and exercising** (see next page).

Eating Well After Cancer Treatment

1. Eat a variety of healthful foods, with an emphasis on foods from plant sources.
    - Eat five or more servings of vegetables and fruits each day.
    - Choose whole grains—rather than processed (refined) grains and sugars.
    - Limit eating red meats, especially high fat or processed meats.
    - Choose foods that help you maintain a healthy weight.
2. Adopt a physically active lifestyle.
3. Maintain a healthy weight throughout the rest of your life.
4. Limit drinking alcohol, if you drink at all.

Source: American Cancer Society Recommendations for Nutrition and Physical Activity for Cancer Prevention, 2002

Exercise After Cancer Treatment

Few studies have been done to find out whether physical activity affects survival after cancer treatment. More research is needed to answer this question, but studies have shown that moderate exercise (walking, biking, swimming) for about 30 minutes every—or almost every—day can:

- Reduce anxiety and depression
- Improve mood
- Boost self-esteem
- Reduce symptoms of fatigue, nausea, pain, and diarrhea

During recovery, 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 moving your arms or legs around—can help you stay flexible, relieve muscle tension, and help you feel better. Some survivors may need to take special care in exercising. Talk with your doctor before you begin any exercise program.

"The more you learn about your cancer, the more you realize you have to speak up for yourself. And lots of times I would take information to my doctor."

Ellen, stomach cancer survivor, 70

Do You Have Trouble Talking With Your Doctor?

It is not always easy to talk with your doctor. Sometimes, he or she uses terms you do not know. When this happens, it is important to stop and ask the doctor to explain what the words mean. You may be afraid of how you will sound to the doctor, but having questions is perfectly normal.

Talking with your doctor is important. Both of you need information to manage your care. Telling the doctor about your health and asking questions helps both of you do your "jobs" well. Here are some points to cover.

At your first follow-up visit, ask your doctor/health care team about:

- The tests and follow-up care you need, and how often you will need them.
- The kinds of physical problems you may have from your cancer treatment and what you can do to prevent, reduce, or solve them.

- The potential long-term effects of treatment and the warning signs that you might have them.
- The warning signs that cancer may be coming back and what to do if you see them.
- Fears you may have about follow-up care.

Keep in Mind

Many survivors want to learn about symptoms that may indicate their cancer has come back, or recurred.

There are many types of symptoms that may show if cancer has returned, and it depends on each person, the kind of cancer she/he was treated for, and the kind of treatment he/she had.

It is for this reason that you should talk to your doctor about the signs or symptoms that you should watch for and what you should do about them.

At each visit, tell your doctor/health care team about:

- Symptoms that you think may be a sign of cancer's return.
- Any pain that troubles you. (See page 24 for ways to describe your pain.)
- Any physical problems that get in the way of your daily life or that bother you, such as fatigue, trouble sleeping, loss of sex drive, or weight gain or loss. (See the section that starts on page 19.)
- Other health problems you have, such as heart disease, diabetes, or arthritis.

- Any medicines, vitamins, or herbs you are taking and any other treatments you are using. (See the section “Complementary and Alternative Medicine,” below.)
- Any emotional problems you may have, and any anxiety or depression you have had in the past. (See the section “Your Mind,” beginning on page 47.)
- Any changes in your family medical history.
- Things you want to know more about (such as new research or side effects).

Your health care team should be able to help you or refer you to someone who can help with any side effects or problems you may have. You have a right to get the help you need.

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. An approach is often called alternative when it is used instead of treatments prescribed by a doctor. Research has shown that more than half of all people with cancer use one or more of these approaches.

Some common approaches include: visualization or relaxation; acupressure and massage; homeopathy; vitamins or herbal products; special diets; psychotherapy; spiritual practices; and acupuncture.

Even though you have finished your cancer treatment, if you are thinking about using these methods, discuss this decision with your doctor or nurse. Some complementary and alternative therapies may interfere or be harmful when used with treatments normally prescribed by a doctor.

Tips: Getting the Most From Your Follow-up Visits

How do you get the most from your doctor visits? Here are some ideas that have helped others deal with their follow-up care:

- Ask someone to come with you to your doctor visit. 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.
- Bring paper or a tape recorder to make note of the answers the doctor gives you.
- Ask your most important questions first in case the doctor runs out of time.
    - Don't be afraid to ask the doctor if you can schedule more time when you set up 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.
      Example: "I am tired most of the time each day. I've tried napping, but it does not help. My fatigue gets in the way of my daily life, which makes me upset and angry. I would like you to help me treat this problem or refer me to someone who can help."

- Tell your doctor how much you want to know.
    - Tell him/her when you’ve heard enough or when you want more information.
    - Ask for booklets or other materials to read at home.
- Make sure you understand the doctor’s answers.
    - Repeat in your own words what you think the doctor meant.
    - Ask the doctor to explain what he or she said in terms you understand.
- If you find you cannot get answers to your questions, let your doctor know you’re unhappy about it. If that does not get results, you may want to try to find a new doctor. This can be hard to do, but getting the information you need is important for your health.
- Ask your pharmacist about how to take your medicines correctly or about possible side effects.
- Keep your own set of records about the follow-up care you get. (See box on the next page.)

Tell any other doctor 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. Other doctors you see may not know about your cancer and its treatment unless you tell them.

Your Medical Records

Make sure to get a copy of your cancer treatment records or a summary. (You may be charged for these.) By keeping your records up to date, you'll have enough information to share with any new doctors you may see.

If you don't keep a copy, your records might be spread among many doctors' offices, and key facts about your cancer history could be lost.

Here are the key types of records you'll want to keep:

- The type of cancer you were treated for
- When you were diagnosed
- Details of all cancer treatment (including all surgeries; names and doses of all drugs; sites and total amounts of radiation therapy; and places and dates of treatment)
- Key lab reports, pathology reports, and x-ray reports
- Contact information for all health professionals involved in your treatment and follow-up care
- Any problems that occurred after treatment
- Information on supportive care you had (such as special medications, emotional support, and nutritional supplements)

Services to Think About

People who have had cancer agree that no one should have to go it alone after treatment. Your friends and family can help. Ask your doctor, nurse, social worker, or local cancer organization how to find services in your area like the ones listed below.

Professional Support Services You May Need

Service	How It Can Help You
Clergy—Spiritual Counseling	Some members of the clergy are trained to help you deal with cancer concerns such as feeling alone, fear of death, searching for meaning, and doubts about faith.
Couples Counseling	You and your partner can 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.
Family Support Programs	Your whole family may be involved in the healing process. In these programs, you and your family members participate 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 advise on whether to have gene testing for cancer and how to deal with the results. It can be helpful for you and for family members who have concerns for their own health. See page 103 for ways to find genetic counselors.
Home Care Services	State and local governments offer many services useful after cancer treatment. A nurse or physical therapist may be able to come to your home. You also may be able to

Home Care Services (continued)	get help with housework or cooking. The phone book has contact numbers under Social Services, Health Services, or Aging Services—both nonprofit and for-profit.
Individual Counseling	Trained mental health specialists 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 a few 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. You may want to ask your doctor if there are 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 independent 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.
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.

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Physical Therapists	Physical therapists are trained in the way that the body parts interact and work. They can teach you about proper exercises and body motions that can help you gain strength and mobility after treatment. They can also advise you about proper postures that help prevent injuries.
Smoking Cessation Services	Research shows that the more support you have in quitting smoking, the greater your chance for success. Many communities have "quit smoking" programs. Ask your doctor, nurse, social worker, or local hospital about what is available, or call 1–800–4–CANCER (1–800–422–6237).
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 such programs and classes.
Support Groups for Survivors	In-person and online groups enable survivors to interact with others in similar situations. (See pages 61-64.)
Vocational Rehabilitation Specialists	If you have disabilities or other special needs after treatment, these services can help you find suitable jobs. Such services include counseling, education and skills training, and help in obtaining and using assistive technology and tools.

Your Body After Cancer Treatment

Your Body After Cancer Treatment

"If I could get over the physical part, if it would stop hurting, I think I would be fine."

Rose, lung cancer survivor, 70

Although your treatment has ended, you are still coping with how it affects your body. It can take time to get over the effects of cancer treatment. Each person's schedule is different. You may wonder how your body should feel during this time and what may be a sign that cancer is coming back. This section talks about some of the problems that can occur when treatment is over. Some of the most common effects people report are:

- Fatigue
- Pain
- Lymphedema, or swelling
- Problems with their mouth or teeth
- Problems with weight and eating
- Loss of bladder or bowel control
- Menopause symptoms
- Changes in their sex lives

What you experience may be related to the type of cancer you had and the treatment you received. It is also very important to remember that no two people are alike, so you may experience changes that are very different from someone else's, even if they had the same type of cancer and received the same treatment.

Fatigue

"I can walk and keep busy," said one testicular cancer survivor, *"but it gets very tiring. If I sit in a chair and really want to read or watch something, I'm gone in about 30 seconds, and it is a deep sleep."*

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

Rest or sleep does not "cure" the type of fatigue you may have after cancer treatment, and doctors do not know its exact cause(s). The causes of fatigue are different for people who are receiving treatment than they are for those who have completed treatment:

- 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), poor nutrition, not drinking enough liquids, and depression. Pain can also 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. Others, such as those who have had bone marrow transplants, may have less energy for years after their final treatment.

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

Getting Help With Fatigue From Your Doctor or Nurse

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

See pages 121-124 for relaxation exercises to try.

- 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 skills
- 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

Tips: Fighting Fatigue

How do you fight fatigue? Here are some ideas that have helped others:

- 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 do not tire you out. Try to read something brief or listen to music.

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- Let others help you. They might cook a meal, pick up something at the store, 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.
- Just say "no" to things that do not matter as much to you now. This may include housework and other chores. By using the energy you have in rewarding ways, you can live a fuller life.
- Think about joining a support/education group for people with cancer. (See pages 61-64.) Talking about your fatigue with others who have had the same problem can help you learn new ways to cope.

Pain

You may have pain after treatment. In some cases, it is caused by the treatment itself.

Types of pain you may feel following cancer treatment include:

- **Skin sensitivity where you received radiation.** This type of pain is quite common and can last for many months. *"I am so sensitive [there] that I cannot put on anything tight,"* one breast cancer survivor noted.
- **Pain or numbness in the hands and feet due to injured nerves.** Chemotherapy or surgery can damage nerves, which can cause severe pain. (This is called neuropathy.)
- **Painful scars from cancer surgery.**
- **Pain in a missing limb or breast.** While doctors do not know why this pain occurs, it is real. It is not just "in your mind."

Getting Help With Pain From Your Doctor or Nurse

You deserve to get relief from your pain, and your doctor or nurse can help you. Wanting to control pain is not a sign of weakness. It is a way to help you feel better and stay active.

If you are older, you may not know whether your pain is because of cancer or because of other health problems, such as arthritis. You might not think to mention it to either your oncologist or your other doctors, but you should do so. If you are in pain, tell your oncologist or another doctor.

With your help, your doctor can assess how severe your pain is. Then, he or she might suggest one or more of the following approaches. These approaches have helped others recovering from cancer and may help you.

- **Pain relief medicines.** In most cases, doctors will try the mildest medicines first. Then they will work up to stronger medicines 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 medicines you'll become a "drug addict," but this almost NEVER happens if you take the correct dose and see your doctor regularly.
- **Antidepressant medicines.** Some of these have been 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.

Health insurance does not always cover these approaches. Find out whether your policy covers the approaches your doctor recommends.

- **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 helped relieve their pain or reduced their stress. See pages 26 and 121-124 for more information.
- **Nerve blocks or surgery.** If you do not get relief from the other approaches in this section, you may want to ask the 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.

Tips: Talking to Your Doctor About Pain

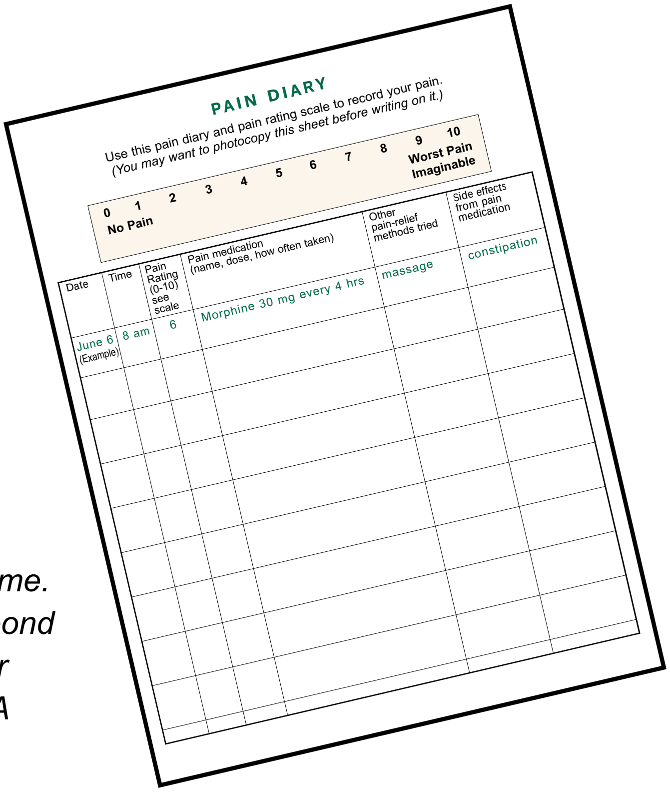
Here are some tips to help you describe your pain to your doctor:

- 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.

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

- 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 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 your 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 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 solved.
- Talk about your goals for pain relief. Do you want no pain at all (which can sometimes be hard to achieve), or is your goal to feel well enough to do specific activities?



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 **No Pain**	1	2	3	4	5	6	7	8	9	10 **Worst Pain Imaginable**

Date	Time	Pain Rating (0-10) see scale	Pain medication (name, dose, how often taken)	Other pain-relief methods tried	Side effects from pain medication
June 6 (Example)	8 am	6	Morphine 30 mg every 4 hrs	massage	constipation

Keep a pain diary. A diary can help you track changes over time. It can also show how you respond to any pain control medicine or other treatment you receive. (A large version is on page 120.)

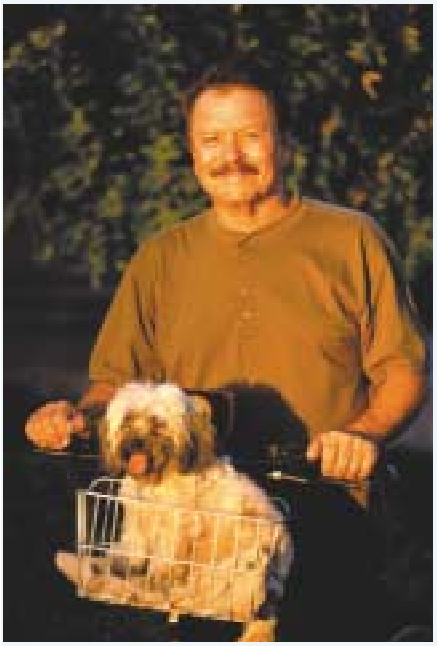
Tips: Practicing Relaxation to Relieve Pain and Stress

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 try the exercises on pages 121-124, take a class, or buy a relaxation tape or CD.

Finding Humor and Laughing As Much As You Can



"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, kidney cancer survivor, age 56

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:

- Enjoy the funny things children and pets do.
- Watch funny movies or TV shows.
- 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.
- Go to comedy shows.

You may even find you can laugh at yourself. *"I went by to help a friend with her computer this summer, and it was really hot, so I took my wig off,"* one woman said. *"I got ready to go and I could not find my wig. Well, her toy poodle had gotten it and had done a number on it, [but] I just stuck it on and went home. My husband said, 'What happened?' Needless to say that wig has never been the same."*

Lymphedema: Arm or Leg Swelling

Lymphedema is a swelling of a part of the body, usually an arm or leg, that is caused by the buildup of lymph fluid. It can be caused by cancer or the treatment of cancer. 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. Lymphedema 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. Your risk is even higher if you 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 were treated with 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 With Lymphedema From Your Doctor or Nurse

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

- **Ways to keep your skin healthy.** It is important to keep your skin clean. You should also keep it moist with lotion.
- **Exercising** to help the body drain the lymph fluid, and what types of exercise you should not do.
- **Treating lymphedema.** He or she may suggest:
  - Keeping the arm or leg raised above your chest.
  - Special massage that can help by moving the lymph fluid from where it has settled.
  - Special bandages and clothing that can help lymph fluid drain.
  - Losing weight.
- **Finding sources of emotional support** to help you cope.

Tips: 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, or 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.
- Try not to use that arm or leg to figure out how hot or cold something is—such as bathwater or cooked food. You may be less able to feel hot and cold now.

See page 7 for more information about eating well.

Problems With Your Mouth or Teeth

Research shows that many people who have been treated for cancer develop problems with their mouth and teeth.

Radiation 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. This can cause:

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

If you were treated with certain types of chemotherapy, you can also have many of the same problems.

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.

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 2 of every 5 people treated with chemotherapy

Getting Help With Your Mouth or Teeth Problems

If you find that these problems persist after cancer treatment ends, talk to your doctor about:

- What may be causing these problems
- Ways to control mouth pain

See your dentist soon after you are done with treatment. Ask about:

- How often you should have checkups
- Ways to take care of your mouth and teeth

Tips: Preventing or Relieving Mouth or Teeth Problems

Keep your mouth moist.

- Drink a lot of water.
- Suck 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.
- Use a mild fluoride toothpaste (like a 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 one 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.

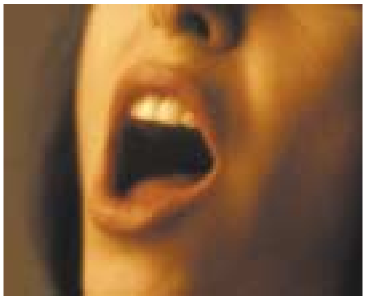
For ways to make chewing and swallowing less painful, see page 35.

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

- Sharp, crunchy foods, like taco chips, that could 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 could cause cavities
- Toothpicks (they can cut your mouth)
- All tobacco products
- Alcoholic drinks

If you have stiffness in your jaw:

- Three times a day, open your mouth as far as you can without pain, then close it. Repeat 20 times.



Weight Changes

"I cannot believe I have cancer, and I'm gaining weight!"

Sara, breast cancer survivor, 43

Research shows that some cancer survivors who have had certain kinds of chemotherapy or who have taken certain medicines have problems with weight gain—and 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.

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

Getting Help With Weight Gain From Your Doctor or Nurse

Your doctor or nurse can help you deal with weight gain. Ask about:

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

Tips: 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. Try to have a smaller breakfast than usual, then have a healthy snack in the middle of the morning.
- Focus on favorite foods. If the thought of eating still lacks appeal, try the foods you really liked before treatment. They can help jump-start your appetite.
- Pamper yourself. Make mealtime a special time. Even if you only have a nutritional supplement drink, serve it in a chilled glass or mug. Add some fresh fruit, juice, or other flavor boost to make it taste better.
- Find ways to make your meals look nice. Choose foods of contrasting colors; serve the meal on a pretty plate; use a colorful napkin.

For tips about eating well after treatment, see page 7.

If You Have Trouble Swallowing

Some people who have had radiation therapy or chemotherapy to the head or neck areas may find it hard to eat because they have trouble swallowing. People who have had radiation to the breast or chest or those who have had surgery involving the larynx may also have this problem. As one lung cancer survivor said, *"I had a really hard time swallowing and chewing because of the chemo. I just couldn't do it. I lived on soup and soft rice for weeks and weeks."*

If you have trouble swallowing:

- 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.

Bowel and Bladder Control

Bowel and bladder 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. *"I felt so foolish having to go to the bathroom all the time. And it was a complete surprise. My doctor never told me I would have this problem."*

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 bowel or bladder 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 With Bowel and Bladder Control From Your Doctor or Nurse

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

- Help in dealing with ostomies. There are services and support groups to help people deal with these changes.
- Problems with constipation, which can be treated.
- Doing Kegel exercises (see page 42) and other physical training programs.
- Medications that may help.

Menopause Symptoms

After chemotherapy, some women stop getting their periods every month—or stop getting them altogether.

Some cancer treatments (and the medicine tamoxifen) can cause changes in women's bodies and reduce the amount of hormones the body makes. 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.

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 disrupt sleep. This can cause mood changes and make it hard for you to make decisions.

Problems with your vagina or bladder. Tissues in these areas become drier and thinner. You may be more likely to get infections in your vagina. As you get older, you may also have urinary tract problems or problems holding your urine.

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.

For more information about getting help for sexual problems related to menopause, see page 42.

Memory problems, 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 in your skin.

It Is Important to Know That:

If you were still getting your period when you started treatment,

and

you are having menopause symptoms after treatment,
you *still* may be able to get pregnant.

Getting Help With Menopause Symptoms From Your Doctor or Nurse

See a gynecologist every year. Ask about:

- Medicines or 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 in your blood, which can increase your risk of diseases that affect your heart and blood vessels.

Tips: Relieving Menopause Symptoms

Here are some tips that have helped others deal with menopause symptoms:

- Quit smoking.
- Exercise—both weight-bearing and muscle-strengthening.
- Eat wisely. A balanced diet will provide most of the nutrients and calories your body needs to stay healthy.
- Through exercise and diet, try to maintain a healthy weight.
- Drink plenty of water.

If you are having hot flashes, try making a diary of when they happen and what may start them. This may help you find out what to avoid. Otherwise:

- When a hot flash starts, go somewhere that is cool, or carry a small fan with you.
- Sleep in a cool room; this may keep hot flashes from waking you up during the night.
- 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 (water or juice) at the beginning of a flash.
- Try not to eat a lot of spicy foods. Limit the alcohol and caffeine you drink.

For tips on eating and exercise, see page 7.

Intimacy and Sexuality

"I knew about the impotence. What I did not know about … was the total lack of interest, which really caused some problems between [me and my partner]."

Mitch, prostate cancer survivor, 73

You may have changes in your sex life after cancer treatment—many people do. 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 pain medicine. Sometimes these problems are caused by depression, feelings of guilt about how you got cancer, changes in body image after surgery, and stress between you and your partner.

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

- **Losing interest in sex.** Some may struggle with their body image after treatment. Even thinking about their partners seeing them without clothes is stressful. Others are worn out or in pain, and sex is the last thing on their minds. Chemotherapy and some cancer medicines can also reduce 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, like chemotherapy, surgery, or radiation, can cause these problems; sometimes, there is no clear cause for these problems.
- **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 the type of treatment you had, your sex and age, and the length of time you've been out of treatment, you may still be able to have children.

See pages 37-39 for more information about menopause.

Getting Help With Sexual Problems From Your Doctor or Nurse

Your doctor may be able to help you deal with these problems, but he or she may not bring up the subject. You may need to "break the ice" yourself. If you think you might have trouble getting started, bring this booklet with you and show this section to your doctor or nurse.

Often, sexual problems will not get better on their own. To get help with many of these problems, it is important to talk to your doctor. Ask about:

- **Any medical problem that may be causing changes in your sex life.** You may be able to get treatment for the problems you are having. These may include:
  - **Erection problems.** Medicines, counseling, finding ways to please yourself, surgery, or other approaches may help.
  - **Vaginal dryness.** Dryness or tightness in the vagina, which 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.
- **Ways you can gain muscle control by doing Kegel exercises.** You can help strengthen muscles in your genital area by doing these 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.

- **Concerns about having children,** and what you can do. Discuss family planning concerns with your doctor. If you are a woman, ask if you still need to use birth control even if you are not getting your period.
- **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.

Tips: Feeling Intimate After Treatment

Most people can still enjoy sex and intimacy after cancer treatment, even if they need to make changes. Here are some ideas that have helped other people.

- **Create a sensual mood.** Lighting, music, scent, or a romantic meal for two can help.
- **Have a "date."** If possible, set aside special time for just the two of you.
- **Touch each other.** Kiss, hug, and cuddle even when you cannot have the kind of sex you are used to having.
  - **Change positions.** A new position may increase your comfort.
  - **Find other ways to be sexual.** For example, you may enjoy feelings in parts of the body that were not touched as often before. Think about ways to give yourself pleasure.
  - **Go slowly at first.** If you have painful scars, you may have to get used to having the scar touched little by little.

For more tips on talking to your partner about sex and intimacy after cancer treatment, see pages 76-77.

- **Ask for more foreplay if you need it.** Some women say they need more time for foreplay to relax and get ready for sex. Some men say they need a new type of caress to reach orgasm. Their climax may be stronger if they stop and start a few times when they get close to climax.
- **Find ways to feel more sensual.** Wear pajamas or a nightgown that hides your scar and makes you feel attractive. Think about all the ways you please your partner.
- **Be positive.** Your thoughts can play a big role in your sex life.
- **Tell your partner about your worries or fears.**

What if I Have Other Health Problems?

For some survivors, the long-term effects of cancer and its treatment may be made worse by the effects of aging, or by other health conditions, such as diabetes or heart disease, that you may have had before cancer. Breast cancer survivors who have had surgery may find everyday activities like reaching or stretching painful; health conditions such as arthritis can make these activities even more difficult. Colorectal or prostate cancer survivors may find that the aging process also affects their bowel or bladder control.

It is very important that you tell your doctor about:

- *All* your health conditions
- *All* the medicines you are taking for these conditions

Some cancer treatments may cause future health problems. Sometimes these problems don't appear right away; some don't appear until *years* after treatment.

Ask your doctor:

- Whether your treatment can put you at risk for short-term or long-term problems
- What those problems are
- What you should do to take care of your health

Your Mind and Your Feelings After Cancer Treatment

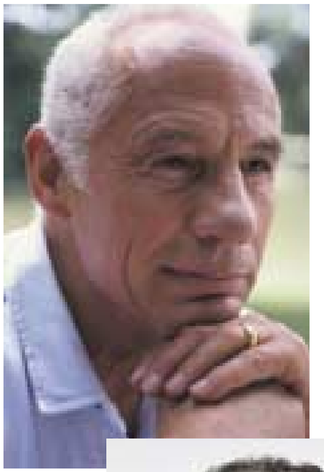
Your Mind and Your Feelings After Cancer Treatment

Just as cancer treatment affects your physical health, it affects the way you feel, think, and do the things you like to do. Besides causing many emotions that may surprise you, the treatment may actually change the way your brain works. 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 unique, and the feelings, emotions, and fears that you have are unique as well. 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 find help from counselors and others outside the family, while others do not feel comfortable with this approach. Whatever you decide, it is important to do what's right for *you* and not compare yourself to others.

Here are some common feelings other people have had after cancer treatment.

Fear That Cancer Will Come Back



"I don't think you ever forget the fact that it is always possible for it to come back."

Grant, leukemia survivor, 68

"As long as I was in treatment, I was killing the cancer. [After treatment] I was waiting for the other shoe to fall."

Judy, breast and thyroid cancer survivor, 45

Worrying about the cancer coming back (recurring) is normal, especially during the first year after treatment. This is one of the most common fears people have after cancer treatment. Even years after treatment, this fear may always be in the back of their minds.

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."* Of course, not everyone reacts this 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 their fear of cancer coming back becomes less, and they find themselves thinking less often about their cancer. However, even years after treatment, some events can cause you to become worried about your health. These may include:

- Follow-up visits
- Anniversary events (like the date you were diagnosed or had surgery or ended treatment)
- Birthdays
- Illness of a family member
- Symptoms similar to the ones you had when you found you had cancer
- The death of someone who had cancer
- Personal reminders. For example, one person said he used to go to a particular restaurant during chemotherapy because the milkshakes they served were the only thing he could stand to eat. After treatment, he found he had to stop going to the restaurant because it reminded him of treatment and made him "sick to his stomach."

Tips: Coping With Fear of Cancer Returning

How do you cope with fear of cancer returning? Here are some ideas that have helped others deal with fear and feel more hopeful:

- **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 feelings of fear, anger, or sadness.** Being open and dealing with their emotions helps many people feel less worried. People have found that when they express strong feelings like anger or sadness, they are more able to let go of these feelings. Some sort out their feelings by talking to friends or family, other cancer survivors, or a counselor. Of course, if you prefer not to discuss your cancer with others, you should feel free not to. You can still sort out your feelings by thinking about them or writing them down on paper.

  Thinking and talking about your feelings can be hard. Some people just want to move on. They put the thought of cancer and all that goes with it out of their minds. While it is

important not to let cancer "rule your life," it may be hard to do. If you find cancer is "taking over" your life, it may be helpful to find a way to express your feelings.

- **Work toward having a positive attitude, which can help you feel better about life now.** Sometimes this means looking for what is good even in a bad time or trying to be hopeful instead of thinking the worst. 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. This is usually not true—and you should not dwell on feeling this way. Remember, cancer can happen to anyone.

  You don't need 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. I … cancel all my appointments. I go upstairs and crawl into bed."*

- **Find ways to help yourself relax.** The exercises on pages 121-124 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 worthwhile can help you focus on other things besides cancer and the worries it brings.

- **Control what you can.** Some people say that putting their lives in order makes them feel less fearful. 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 more power. And, while no one can control every thought, some say they've resolved not to dwell on the fearful ones.

Feeling Stress

When you were diagnosed, you may have put certain issues aside for a while, such as concerns about family, work, or finances. Now that treatments are over, these issues may begin to resurface just when you are tired and may feel that there is already too much to handle.

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

Tips: Reducing Stress

Many survivors have found activities like the ones below useful in dealing with cancer and 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 45 or 50 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 cannot walk, ask about other types of exercise that may be helpful.

Dance or Movement. People can act out their feelings about cancer in classes using dramatic and/or dance-style body movements. Other class members talk about the issues the "performer" was trying to express.

Sharing Personal Stories. Telling and hearing stories about living with cancer can help people learn, solve problems, feel more hopeful, air their concerns, and find meaning in what they've been through. See pages 61-64 for support group information.

Music and Art. Even people who have never sung, painted, or drawn before have found these activities helpful and fun.

Dealing With Depression and Anxiety

After treatment, you may still feel angry, tense, sad, or blue. For most people, these feelings go away or lessen over time. For up to one in four people, though, these emotions can become 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 contributed to this problem by changing the way the brain works.

Getting Help for Depression

Talk to your doctor. If your doctor finds that you do suffer from depression, he or she may treat it or refer you to other experts. Many survivors get help from therapists who are expert in both depression and helping people recovering from cancer. Your doctor also may give you medicine to help you feel less afraid and 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. Do not feel that you should be able to control these feelings on your own. Getting help if you need it is important for your life and your health.

How Do I Know If I Need Help With Depression or Anxiety?

If you have any of the following signs for more than 2 weeks, talk to your doctor about treatment.

Emotional signs:

- A sense of being worried, anxious, blue, or depressed that doesn't go away
- Emotional numbness
- Feeling overwhelmed, out of control, shaky
- A sense of guilt or worthlessness
- Helplessness or hopelessness
- Irritability and moodiness
- Difficulties concentrating, or feeling "scatterbrained"
- Crying a lot
- Focusing on worries or problems
- Not being able to get a thought out of your mind
- Not being able to stop yourself from doing things that seem silly
- Not being able to enjoy things any more, such as food, sex, or socializing
- Finding yourself avoiding situations or things that you know are really harmless
- Suicidal thoughts or feeling that you are "losing it"

Body changes:

- Unintended weight gain or loss not due to illness or treatment
- Insomnia or increased need for sleep
- Racing heart, dry mouth, increased perspiration, upset stomach, diarrhea
- Physically slowing down
- Fatigue that doesn't go away; headaches or other aches and pains (These may also be caused by cancer treatment; see pages 20-22.)

Dealing With Changes in Memory and Concentration

"I tell them it is a 'senior moment,' but I notice I have a lot more of them now, and I'm sure [treatment] had something to do with it," one 70-something survivor noted. *"Not being able to concentrate the way I used to is the worst effect for me,"* a younger survivor added. *"I worry about how it will affect my work."*

Research shows that one in four people with cancer reports memory and attention problems after chemotherapy. More research is needed to learn what causes these changes.

These effects can begin soon after treatment ends, or they may not appear until years later. They do not 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 cannot focus as they once did.

Research is just starting to explore who may develop problems with memory and concentration. It seems that people who have had systemic chemotherapy or have had radiation to the head area are at higher risk of having these problems. People who have had high doses of chemotherapy may be particularly affected by memory problems, but even those who have had standard doses have reported memory changes.

Working With Your Doctor or Nurse on Memory and Concentration Problems

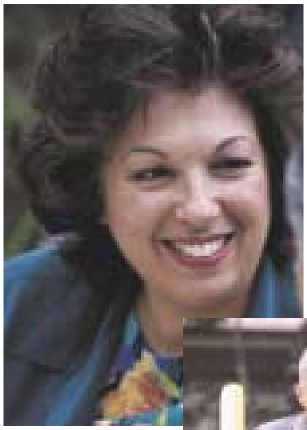
Your doctor can help you with memory and concentration problems. Talk with him or her if:

- 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.

Tips: Improving Memory and Concentration

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

- **Get a notebook or pocket calendar** and use it to plan your day. You can write down each task, how long it will take, and where you need to go. Plan the whole day, including night hours. Keep it simple, and be realistic about how much you can do in a day.
- **Put small signs around the house** to remind you of what you need to do. Use them to remember tasks such as: 1) take out the trash; and 2) lock the door. Hint: use only two or three signs. If you have too many, you may ignore them.
- **Group long numbers** (such as phone numbers and ZIP codes) into "chunks." For example, the phone number 812–5846 can be repeated as "Eight-twelve, fifty-eight, forty-six."
- **"Talk yourself through" something you need to do** to help you stay focused. When doing a task with a number of steps, such as cooking or working on a computer, whisper each step to yourself.
- **Learn relaxation skills.** (See pages 121-124.) Learning how to relax can help you remain calm even in stressful moments. Managing stress better can improve memory and attention.
- **Before you go to family events or work functions, practice saying important information** that you want to remember, like 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.



"Women want to feel like women. And you want to be feminine when you look in the mirror … and especially if you are a single woman."

Sandra, breast cancer survivor, 53

"I just did not feel like my body was the same after treatment. I can't play hard with my grandchildren any more, and we both miss it."

George, non-Hodgkin's lymphoma survivor, 71

Dealing With Body Changes

Some body changes are short-term, and others will last forever. Either way, how you look may be a big concern after cancer treatment. People with ostomies after colon or rectal surgery are sometimes afraid to go out. They may feel shame or fear that others will reject them. They may be afraid they will have an "accident" and feel embarrassed. Others do not like people being able to see treatment effects like scars on the head or neck, skin color changes, loss of breasts or limbs, weight gain or loss, and hair loss. Even if your treatment does not "show," your body changes may trouble you. Feelings of anger and grief are natural. You have lost your "old body" and, with it, your sense of self.

Feeling bad about your body can also lower your sex drive, and the loss of or reduction in your sex life can make you feel even worse about yourself. *"Mentally, it was strange,"* one prostate cancer survivor said. *"You're worried about your 'man thing.' It may be on the back of your mind … but it is always there."* Women also have this concern. *"I felt like I was half of a woman,"* one ovarian cancer survivor noted.

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

Tips: Coping With Body Changes

How do you cope with body changes? Here are some ideas that have helped others:

- If you find that your skin has changed color from radiation, ask your doctor or nurse about ways you can care for your skin and if the color will change over time.
- Find 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.
- Tell yourself that you are more than your cancer. Know that you have worth no matter how you look or what happens to you in life.
- Mourn your losses. They are real, and you have a right to grieve.
- Focus on the ways that coping with cancer has made you stronger, wiser, and more realistic.

Feeling Angry

Many people find themselves feeling angry about having cancer or about things that have 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.

Tip: Feeling Less Angry

✓ *Hanging on to anger can get in the way of your taking care of yourself, but sometimes anger can energize you to take action to get the care you need. If you find yourself feeling angry, find a way to use that energy to help yourself.*

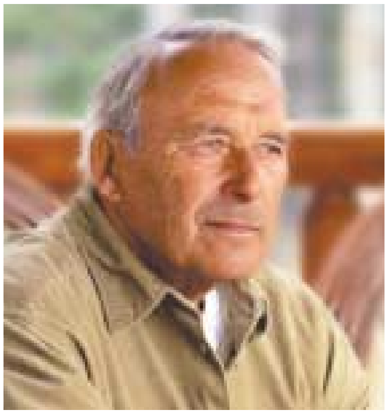
Feeling Alone

"I found myself kind of going through the motions, through the treatments, through the doctor's appointments. I never really stopped to consider the emotional side of things. After I finally realized what I was dealing with, I didn't feel like I had the emotional support I needed."

Carmen, Hodgkin's disease survivor, 25

"I went [to radiation treatment] every day, and they treated me, and we were like … family. And now there's this instant separation."

Tom, prostate cancer survivor, 70



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. You also may feel that only others who have had cancer can understand your feelings. Feelings like these are normal any time you leave people who mean a lot to you.

It is 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.

Tips: Feeling Less Alone

What can you do to make yourself feel better during this lonely time? Here are some methods other people have found helpful:

- Figure out how you can replace the emotional support you used to receive from your health care team. Think about:
  - Asking one of your nurses or doctors if you could call sometimes. Your call 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 are a few ideas.
- Think about joining a cancer support group. In a cancer support group, people who have had cancer meet to talk about their feelings and concerns. Besides airing their own issues, they hear what others have gone through and how other people have dealt with the same problems they are facing. A support group also may help members of your family cope with their concerns.

"Is a Support Group Right for You?" on pages 62-63, may help you figure out whether you would like to join one.

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, breast cancer survivor, 58

"I didn't go to any supports. There was just too much going on in my life at the time."
Rebecca, non-Hodgkin's lymphoma survivor, 65

Support groups can have many benefits. You may feel better about yourself, find a new life focus, have better pain control, make new friends, improve your mood, cope better with your cancer, learn more about cancer, and better deal with the needs of others in your life.

Support groups can:

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

The number one reason people join a support group is to be with other people who have "been there"—not because they do not receive support from friends and family. Some research shows that joining a specific type of support group improves quality of life and enhances survival.

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; others may be open to those with any cancer. Some may be only for women or men, and others may be focused on people in certain ethnic or racial groups. Support groups may be led by health professionals or fellow cancer survivors.

Support groups are not 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 "on line." These Internet support groups can be a big help to people with computers who live in rural areas or who have trouble getting to meetings. With Internet groups, you can seek support at any time of the day or night. While these 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. Check with your doctor before making any changes based on what you read.

Is a Support Group Right for You?

For some people, hearing about others' problems can make them feel worse. *"I went to the [group] meetings for a while,"* one woman reports. *"I would come out and be so depressed. Why? Because you think you're sick, and you hear the stories; they're like horror stories. I cried enough at home, and I didn't want to go to a group and cry more."*

Could a support group help you? If you answer yes to most of the questions that follow, you may want to try one out. To find groups that meet near you, ask your doctor, nurse, social worker, or local cancer organization.

- Do you enjoy being part of a group?
- Are you ready to talk about your feelings with others?
- Do you want to hear others' stories about their cancers?
- Would you like the advice of others who have gone through cancer treatment?
- Do you have helpful advice or hints to offer others?
- Would reaching out to support other cancer survivors make you feel better?
- Would you be able to work with people who have different ways of dealing with cancer issues?
- Do you want to learn more about cancer and post-treatment issues?

Choosing a Support Group

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 you are not happy with a support group you join, you may want to try finding another group with different members or concerns. Support groups vary greatly, and one bad experience doesn't mean they are not a good option for you.

If a support group does not interest you, think about finding 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.

Finding Meaning After Cancer Treatment

"After waking up in the recovery suite after my surgery … I [felt I] had come through from the other side, and it was not that bad. It truly was the first day of the rest of my life, and it was now up to me to make this new beginning meaningful. I soon realized that the best thing I could do for myself was to help others make the 'journey' that I did."

Michael, prostate cancer survivor, 50

"A process of assessing the 'values' of [my past life] took place. I did not want to stay in the 'sick' world, but my former world seemed so superficial."

Ronnie, colon cancer survivor, 62

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. *"[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,"* one woman said. Others report feeling lucky or "blessed" to have survived treatment and take new joy in each day. For some, the meaning of their illness comes out only after they have been living with cancer for a long time; for others, the meaning changes over time. It also is 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 also might find that going through a crisis like cancer gives you new power and pride. *"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 new skills, and I now know I have strength."*

Cancer survivors often report that they look at their faith or their spirituality in a new way. For some, it may get stronger or seem more vital. Others may question their faith and wonder about the meaning of life. The section on faith (page 67) discusses how some survivors have connected with their spirituality and ways it helped them cope. A new focus on the present is common, too. *"I used to be goal-oriented, knowing what I was doing and what I intended to achieve during a given period,"* one prostate cancer survivor explained. *"And now that is history; I take it day by day."*

Tips: Finding Meaning in Life After Cancer

How do you find new meaning in your life after cancer? Here are some ideas that have worked for other cancer survivors.

- **Talk to a member of the clergy.** Local cancer organizations may be able to help you find clergy in your area who have experience/training helping cancer survivors deal with life questions. See the section on faith (page 67) for ways to connect with others through religion.
- **Keep a journal.** Write down your thoughts about what gives meaning to your life now.
- **Think about helping others who have had cancer.** *"I think too many cancer survivors, after treatment, just want to get it behind them,"* one leukemia survivor said. *"Yet they could be a great help to others through supporting other survivors."* Many local and national cancer groups need people to help. Or, you may prefer to reach out to people you know or friends of friends. Of course, you need not feel this is your "duty," but many say that helping others helps them find meaning in having had cancer. (See other booklets in the NCI *Facing Forward* series for more information.)
- **Take a new look at old patterns.** Some survivors say their cancer gave them a "wakeup 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 have you NOT done that you most want to try? Are you happy in your job, or are you just used to 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 you could benefit both yourself and others. If you want to learn more about studies that involve cancer survivors, talk to your doctor.

Finding Meaning Through Faith, Religion, or Spirituality

Dealing with a serious illness can affect one's spiritual outlook, whether or not one feels 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 have to endure such a trial in your life.

At the same time, many survivors have found that their faith or religion or sense of spirituality is a source of strength as they face life after cancer treatment. Many survivors 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 to others in their community who may share similar experiences or outlooks or who can provide support. Many survivors have found that religious gatherings helped them meet new people and find support through a trying time. Studies have also shown that for some, religion can be an important part of both coping with and recovering from cancer. As one survivor said, *"My faith in God helps me hold life together. I would feel lost, afraid, and wandering about without it. I know that I am in God's hands, and that helps me feel secure. He gives me strength."*

The way cancer affects one's faith or religion is different for everyone. Some turn away from their religion because they feel it has deserted them. It is common to question one's faith after cancer. *"I had to wonder why a loving God would let people suffer like this,"* one brain cancer survivor said. *"I just felt that God had failed me."* These are difficult questions, but for some, seeking answers and searching for personal meaning in spirituality helps them cope.

Here are ways you may find comfort and meaning through your faith or religion:

- Reading religious materials that are uplifting and can help you feel connected to a higher power
- Praying or meditating to help you feel less fearful or anxious
- Talking about your concerns or fears with a religious leader
- Going to religious gatherings to meet new people
- Talking to others at your place of worship who have had similar experiences
- Finding resources at a place of worship for people dealing with chronic illnesses like cancer

Tips: Finding Faith-Based Support

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

- **Contact a religious leader in your community**. Most spiritual leaders 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 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.

Your Social Relationships After Cancer Treatment

Your Social Relationships After Cancer Treatment

"My husband works a lot of hours …. He did not know there was a dishwasher, a washing machine, or any of that, and I really did not call on him during that time. You resent it in some ways."

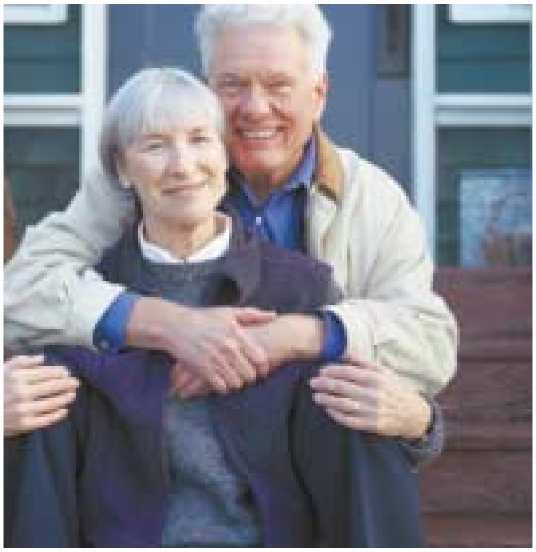
Robin, uterine cancer survivor, 56

Dealing with an illness like cancer can change your relationships with the people in your life. It is 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.

This section talks about some of the issues cancer survivors face in relating to family members, partners and dating, friends, and coworkers after treatment.

Issues With Your Family

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 these jobs too much to handle after treatment has ended. Yet, family members who took over for you may want life to go back to normal and have you do what you used to do around the house. You may then get angry because you are not getting the support you need.



> *"I think some marriages become stronger because of it. We've had our rough spots, but we have never again taken each other for granted."*
>
> Darryl, multiple myeloma survivor, 74

Other times, you may expect more of your family than you receive. They disappoint you, and it can also make you angry. For one woman, it was a family member's lack of support during her treatment. *"Never once, not a card, not a phone call, and I have a hard time looking at her today."*

You may see your role as taking care of others, not being taken care of, yet you may need to depend on others during this time. You may resent it and get angry at those who are just trying to help. You may not know how to talk to your children or grandchildren about your cancer.

When treatment ends, families often are 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 the time they needed to recover. This can lead to disappointment, worry, and frustration for everyone. Families also may not realize that the way the 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 from falling apart.

Now That I've Had Cancer, What Do My Family Members Need to Know About Their Risks?

You may fear that passing your genes on to your children means they will get cancer. One woman felt guilty about getting cancer and what it might mean for her family. *"I have a daughter, and I'm sure she's blaming me for putting her [at] risk."*

It is important to know that most cancer is not passed down through families. Only about 5 to 10 percent of the most common cancers (such as breast, colon, 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
- Different kinds of cancers
- 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 if the cancers that occur in your family are due to genes or to other factors. See page 103 for ways to find genetic counselors.

Getting Help With Family Issues

Some family members may have trouble adjusting to changes or feel that their needs are not being met. Your family may want to deal with issues such as these on its own, or you may want to consider getting outside 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 can help your family solve its problems.

Tips: Dealing With Family Issues

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

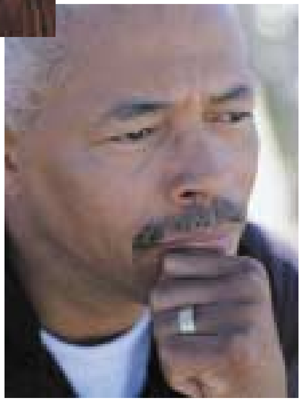
- Let others know what to expect of you as you heal—and what not to expect. Do not feel you must keep the house or yard in perfect order because you always did in the past. Let people know what you can and cannot do.
- Give yourself time. You and your family may be able to adjust over time to the changes cancer brings. Just being open with each other can help ensure that each person's needs are met.
- Help your children (or grandchildren) understand that you were treated for cancer. 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.

Issues With Partners and Dating

"My boyfriend left. He is a wimp. He would not even touch me, and never wanted to talk about my cancer. I wonder if I can ever trust again."

Joyce, cervical cancer survivor, 40



"Having cancer helped me find new ways of feeling close."

Arthur, bladder cancer survivor, 52

Body changes and concerns about sex can affect the way you relate to your partner or how you feel about dating. As you struggle to accept changes yourself, you may also worry about how someone else will react to scars, ostomies, sexual problems, and loss of fertility. Sexual problems can make feeling close even harder. Even for a couple that has been together a long time, staying connected can be a major challenge at first. It may be a comfort 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.

If you are single, you may wonder how and when to tell a new person in your life about your cancer and body changes. Fear of being rejected keeps some people from seeking the social life they would like to have. Others do not want to date and prefer to be alone but may face pressure from friends or family to "be more sociable."

Getting Help With Partner and Dating Issues

If your concerns about sex or dating persist, think about seeing a sex therapist or a counselor. He or she may be able to help you work through personal issues and prepare you to talk with your partner or a new person in your life.

✓ Tips: Talking to Your Partner About Your Sexual Needs

How do you talk to your partner about sex after cancer treatment? Here are some ideas that have helped others:

Tell your partner how you feel about your sex life and what you would like to change. You might tell him or her:

- What is happening with your sex life
- Your thoughts and beliefs about why your sex life is the way it is
- How it makes you feel—for example, scared, lonely, sad, or angry
- What would please you or make you feel better

This approach avoids blame, stays positive, and gives your significant other a better sense about how you are feeling. Here is an example of how you can talk to your partner:

- *"We have made love only a few times since my cancer treatment* (fact).
- *I think it may be because my scars are a problem for you* (your belief).
- *When we do not have sex, I feel very lonely, and I miss being close to you. Sometimes I also feel angry that cancer affects our sex life, too* (your feelings).
- *I would feel much better if we had sex more often—and if it was your idea more often* (your needs)."

Listen to your partner's point of view:

- Repeat what he or she says in your own words to show you understand.
- Ask questions to show interest and caring.
- Show support. Say things like, *"You seem worried,"* or *"I'm sure this is very hard for you."*
- Listen. Focus on your partner's comments, not on what you plan to say in response.

For more tips about intimacy and sexuality, see pages 40-47.

Tips: Dating After Cancer Treatment

How do you start dating after cancer treatment? Here are some ideas that have helped others:

- Start by working on other areas of your social life besides dating and sex. Make an effort to see friends and family. Try a new activity. Join a club. Take a class. These activities can increase your comfort level in being around people.
- Make a list of your good points. Focus on what you bring to a relationship.
- Try not to let cancer be an excuse for not dating or trying to meet people.
- Do not tell a new date about your cancer right away. Wait until you feel a sense of trust and friendship, but do not wait until you are about to have sex.
- 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 a "success." If some people reject you (which can happen with or without cancer), you have not failed.
- Remember that not all dates "worked out" before you had cancer.

Issues at Your Workplace

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

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 cancer survivors feel they are getting back to the life they had before being diagnosed with cancer.

Some cancer survivors may find themselves changing 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. For more information on your legal rights, see pages 89-91.

Tips: Handling Problems at Work

Decide how to handle the problem.

- What you want to do?
- Do you still want to work there?
- Are you willing to take action to correct a problem?
- 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, flex-time, 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.
- Contact your local cancer support organization, groups for disabled workers, or the local bar association for names of qualified lawyers who specialize in antidiscrimination law. (See resources on pages 89-91.)

Issues With Friends and Coworkers

"When people say you look great, don't you want to hit them?"

Alice, brain cancer survivor, 50

The response of friends, coworkers, and/or people at school after your cancer treatment can be a major source of anger, grief, or dismay. Some people mean well, but they do not know the right thing to say. Maybe they just do not know how to offer support. Others do not want to deal with your cancer at all, even though it is still a daily challenge for you. *"When you say the 'C' word, it just turns [some people] right off, and [they] will mumble something and … walk off,"* one survivor said.

Friends' and coworkers' seeming lack of support may 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 do not want to smile any more,"* one melanoma survivor said. *"You do not have the energy to put up with that."* A prostate cancer survivor noted that: *"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 weak friendships go to give more time to the strong ones. One brain cancer survivor found that after cancer, *"You really know how many true friends you've got. And they do not 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 did not expect from people at work and in church."*

On the job or where you volunteer, people may not understand about cancer and your ability to perform while recovering from treatment. They may expect you to "slack off" or think that your having had cancer means you are going to die soon. Sometimes, fears and lack of knowledge result in unfair treatment. (See pages 89-91 for legal resources.)

Getting Help With Issues Involving Friends and Coworkers

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 such efforts don't help in the job setting, you may want to get help. Your manager, shop steward, company medical department, employee assistance counselor, or personnel office may be able to change coworkers' ideas, procedures, or the way your job fits in with others' to lessen problems.

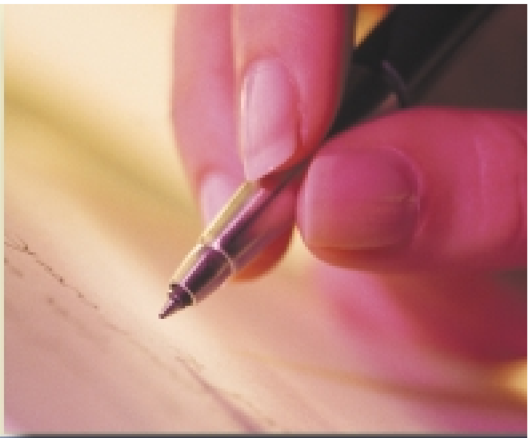
When hurtful remarks or actions get you down, talking to a friend, family member, or counselor may help you deal with it. But if coworker attitudes get in the way of your doing your job, it is a problem management needs to address.

Tips: Relating to Others

How do you relate to other people in your life after cancer treatment? Here are some ideas that have helped others:

- **Accept help.** When friends or family offer to help, say yes, and have in mind some things that would 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 or send e-mail. 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 the 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.

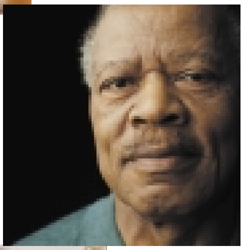
Dealing With Practical Matters After Cancer Treatment



Dealing With Practical Matters After Cancer Treatment

"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, leukemia survivor, 53



"Now if I change insurance companies and [cancer comes back], am I going to be covered?"

Charles, colon cancer survivor, 63

"I don't have insurance—it was hard enough getting my treatment paid for. Now, how can I pay for the medicines I need?"

Elena, ovarian cancer survivor, 56

Being a cancer survivor can affect your job, your health insurance, your finances, and other practical matters. Often, your doctor, nurse, or social worker can be a good source for answers to your questions. There may be resources in your community that can help you get the services you need. This section lists groups and organizations to help you learn more about these issues and solve problems you may have.

You can use the phone or Internet to contact these groups. When you call, have a pen and paper ready to write down important information. If you talk with someone, ask for his or her name in case you want to call back later. If you want to use the Internet but don't have a computer at home, you may want to use one at your public library. The librarian can help you find sites and print out information that you want to take home.

General Cancer Resources

The organizations listed below are a good starting point to answer your questions about cancer. If you want to find a group that deals with a certain kind of cancer, most of these organizations will be able to help you.

General Cancer Resources

Contact Information	Description
National Cancer Institute **Cancer Information Service (CIS)** *To speak with a CIS information specialist:* Tel: 1–800–4–CANCER (1–800–422–6237) 9:00 a.m. to 4:30 p.m. local time, Monday through Friday TTY: 1–800–332–8615 *To get assistance on line:* http://cancer.gov/cis Click on the *LiveHelp* link between 9:00 a.m. and 5:00 p.m., Eastern time, Monday through Friday. **For information 24 hours a day, 7 days a week:** • Tel: 1–800–4–CANCER and select option 4 to hear recorded information • http://cancer.gov	The Cancer Information Service (CIS) is the National Cancer Institute's link to the public, interpreting and explaining research findings in a clear and understandable manner. The CIS can respond to your specific questions about cancer, including ways to prevent cancer, how to quit smoking, symptoms and risks, diagnosis, current treatments, and research studies. Whether you use the phone or the Internet, you can speak with knowledgeable, caring staff who are trained to explain medical information in terms the public can easily understand. You can also get: • Free written materials on many different cancer topics. • Referrals to clinical trials and cancer-related services such as treatment centers, mammography facilities, or other cancer organizations. • Assistance in quitting smoking from information specialists trained in smoking cessation counseling.
Office of Cancer Survivorship http://dccps.nci.nih.gov/ocs/default.html	NCI's Office of Cancer Survivorship provides information on new and innovative research in cancer survivorship and links to information on Follow-Up Medical Care After Cancer Treatment, Late Effects, Health & Well-Being, and Getting Involved After Cancer Treatment.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

General Cancer Resources (continued)

Contact Information	Description
American Cancer Society **(ACS National Headquarters)** 1599 Clifton Road, NE Atlanta, GA 30329-4251 http://www.cancer.org **National Cancer Information Center** *To speak with a cancer information specialist:* Tel: 1–800–ACS–2345 (1–800–227–2345) Call 24 hours a day, 7 days a week. Staff can accept calls in either English or Spanish and can distribute publications in English and Spanish.	The ACS is a volunteer health organization that offers a variety of prevention and early detection programs, as well as cancer information and support to patients, their families, and caregivers. The ACS also supports research, provides printed materials, and conducts educational programs. A local ACS unit may be listed in the white pages of the phone book under "American Cancer Society." **ACS-Supported Programs:** • **Cancer Survivors Network** (http://www.acscsn.org) This is both a telephone and Web-based service for cancer survivors, their families, caregivers, and friends. The telephone component (1–877–333–HOPE) provides survivors and families access to prerecorded discussions. The Web-based component offers live online chat sessions, virtual support groups, prerecorded talk shows, and personal stories. • **Look Good … Feel Better** (http://www.lookgoodfeelbetter.org) In partnership with the Cosmetic, Toiletry, and Fragrance Association Foundation and the National Cosmetology Association, this free program teaches women cancer patients beauty techniques to help restore their appearance and self-image during chemotherapy and radiation treatments. • **Hope Lodge** Housing is provided in some areas through funds raised specifically to purchase lodging for patients during their treatment; 17 lodges are in operation.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

General Cancer Resources (continued)

Contact Information	Description
American Cancer Society (continued)	• **I Can Cope** This program consists of a series of classes in which doctors, nurses, social workers, and community representatives provide information about cancer diagnosis and treatment as well as assistance in coping with the challenges of a cancer diagnosis. • **“tlc”** “tlc” is a “magalog” designed to provide needed medical information and special products for women newly diagnosed with breast cancer and for breast cancer survivors. Many featured products are appropriate for *any* woman experiencing treatment-related hair loss. Free copies are available by calling 1–800–850–9445.
Cancer Care, Inc., National Office 275 Seventh Avenue New York, NY 10001 Tel: 1–800–813–HOPE (1–800–813–4673) Fax: 212–719–0263 http://www.cancercare.org	Cancer Care is a national nonprofit agency that offers free support, information, financial assistance, and practical help to people with cancer and their loved ones. Services are provided by oncology social workers and are available in person, over the telephone, and through the agency's Web site. Cancer Care's reach also extends to professionals, providing education, information, and assistance. A section of the Cancer Care Web site and some publications are available in Spanish, and staff can respond to calls and e-mails in Spanish.
National Coalition for Cancer Survivorship (NCCS) 1010 Wayne Avenue Suite 770 Silver Spring, MD 20910–5600 Tel: 1–877–NCCS–YES (1–877–622–7937) http://www.cansearch.org e-mail: info@cansearch.org	NCCS is a network of groups and individuals that offer support to cancer survivors and their loved ones. It provides information and resources on cancer support, advocacy, and quality-of-life issues. A section of the NCCS Web site and a limited selection of publications are available in Spanish.

Employment and Legal Rights

Could I now be passed over for a promotion? Can my office make special accommodations to make it easier for me to do my job now? These are some of the questions cancer survivors may have when they return to work after treatment. The resource list below offers some general information and specific resources to consult for answers.

NOTE: Legal rights change frequently. Check all the material you read to be sure you are getting accurate and up-to-date information from a reliable source.

Disability and Discrimination

Contact Information	Description
Equal Employment Opportunity Commission (EEOC) 1801 L Street, NW Washington, DC 20507 Tel/TTY: 1–800–669–6820 http://www.eeoc.gov	The EEOC is the Federal agency that coordinates the investigation of employment discrimination. People can bring complaints against employers if they believe they have experienced discrimination.
Federal Laws Prohibiting Job Discrimination: Questions & Answers http://www.eeoc.gov/facts/qanda.html	◀ This fact sheet can answer your questions about who is protected by the ADA, workplace accommodation, and other important information.
The ADA: Your Responsibilities as an Employer http://www.eeoc.gov/facts/ada17.html	◀ This fact sheet describes the responsibilities of an employer toward his/her employees with disabilities.
Department of Justice (USDOJ) 950 Pennsylvania Avenue, NW Washington, DC 20530–0001 Tel: 1–800–514–0301 http://www.usdoj.gov	The DOJ provides information to assist persons with disabilities with legal issues, questions about the ADA, mediation services, and other employment issues.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Disability and Discrimination (continued)

Contact Information	Description
U.S. Department of Labor (DOL) **Office of Disability Employment Policy (ODEP)** 1331 F Street NW, Suite 300 Washington, DC 20004 Tel: 202–376–6200 TTY: 202–376–6205 http://www.dol.gov/dol/odep	This agency provides fact sheets on a wide variety of disability issues, including discrimination, workplace accommodation, and legal rights.
Job Accommodation Network West Virginia University PO Box 6080 Morgantown, WV 26506–6080 Tel/TTY:1–800–526–7234 http://www.jan.wvu.edu	This service of the U.S. Department of Labor offers ideas on how to change a workplace to make it easier for an employee with a disability to do his/her job.
At your workplace: • The Human Resources department • A union representative	The Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (ADA) protect people against employment discrimination based on a disability. These laws often cover cancer survivors.

Legal Assistance

National Employment Lawyers Association (NELA) 44 Montgomery Street Suite 2080 San Francisco, CA 94104 Tel: 415–296–7629 http://www.nela.org	NELA can help find a lawyer experienced in job discrimination cases.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Legal Assistance (continued)

Contact Information	Description
Local Bar Association Check your local phone book.	Many local bar associations provide information about how to find a lawyer and learn about legal assistance in the local area.
Legal Aid or Legal Services Group Check your local phone book.	Many cities have legal aid groups that help provide free or low-cost legal services.

General Legal Information

National Coalition for Cancer Survivorship (NCCS) 1010 Wayne Avenue Suite 770 Silver Spring, MD 20910–5600 Tel: 1–877–NCCS YES (1–877–622–7937) http://www.cansearch.org e-mail: info@cansearch.org	Cancer information, including a book titled *Working It Out: Your Employment Rights as a Cancer Survivor*
American Cancer Society (ACS) 1599 Clifton Road, NE Atlanta, GA 30329–4251 Tel: 1–800–ACS–2345 (1–800–227–2345) http://www.cancer.org	Contact ACS for legal information.
Cancer Care, Inc., National Office 275 Seventh Avenue New York, NY 10001 Tel: 1–800–813–HOPE (1–800–813–4673) http://www.cancercare.org e-mail: info@cancercare.org	Cancer Care has information on a wide range of cancer topics, including employment issues.

Health Insurance Concerns

During treatment, your focus was on getting your health plan to approve your treatments and pay for your care. Now that treatment is over, many people have questions about how their cancer will affect their insurance. Here are some common topics of interest to cancer survivors in the first six months after treatment. Resources for finding out more or getting help are listed for each topic below.

Contact Information	Description
General Information About Your Health Insurance Policy	
National Coalition for Cancer Survivorship (NCCS) 1010 Wayne Avenue, Suite 770 Silver Spring, MD 20910-5600 Tel: 1–877–NCCS–YES (1–877–622–7937) http://www.cansearch.org e-mail: info@cansearch.org	*What Cancer Survivors Need to Know About Health Insurance* is a resource that describes types of insurance, how to buy, how to submit claims, and how to handle claim rejection.
Your Private Insurer	Your insurance company should be able to answer questions about your policy and what it covers. Be sure to ask for answers to questions in writing.
Your State Insurance Office Check the phone book for contact information under “State Government”	Contact your state insurance office about how/where to get new health insurance.
Health Insurance Coverage of Clinical Trials	
National Cancer Institute Tel: 1–800–4–CANCER (1–800–422–6237) http:/www.cancer.gov (click on clinical trials area) TTY: 1–800–332–8615	For more information on health insurance coverage, see the National Cancer Institute’s Web site, or call the Cancer Information Service (CIS).

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Health Insurance—Legal Rights

Contact Information	Description
U.S. Department of Labor (DOL) **Pension and Welfare Benefits Administration** **Office of Public Affairs** 200 Constitution Avenue, NW, Room N-5656 Washington, DC 20210 Tel: 202–693–8664 http://www.dol.gov/dol/pwba (COBRA and ERISA)	Contact the DOL Pension and Welfare Benefits Administration to find out about or confirm your rights under COBRA and ERISA (Federal laws about pensions and keeping insurance coverage when you change jobs).
The Health Insurance Portability and Accountability Act of 1996 (HIPAA) **Centers for Medicare and Medicaid Services (CMS)** 7500 Security Boulevard Baltimore, MD 21244 Tel: 1–800–MEDICARE (1–800–633–4227) www.hcfa.gov (click on HIPAA)	Read here about the Health Insurance Portability and Accountability Act of 1996, which says companies cannot exclude you from group coverage. They also cannot charge more because of past or present medical problems.
State Health Insurance Counseling and Assistance Programs (SHIPS) and other state programs To contact your state programs, call the Medicare hotline. Tel: 1–800–MEDICARE http://medicare.gov	Many states have counseling and assistance programs that can answer your questions and help you understand your health care choices, choose a Medicare plan and/or additional health insurance to meet your needs, and help you understand your rights and protections. You can also contact your state insurance commission by checking the phone book under “State Government.” Ask your doctor, social worker, or pharmacist about programs for which you may be eligible.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Help With Medical Costs

How can I pay for medicines I need? What about free or low-cost in-home medical care or equipment?

For people who do not have health insurance or who need financial assistance to cover health care costs, resources are available, including government-sponsored programs and services supported by volunteer organizations. For more information, contact the organizations listed here.

Financial Assistance

Contact Information	Description
National Cancer Institute Tel: 1–800–4–CANCER (1–800–422–6237) *NCI Fact Sheet: Financial Assistance for Cancer Care* http:/cis.nci.nih.gov/fact/8_3.htm	This fact sheet provides information on financial assistance.
American Cancer Society (ACS) 1599 Clifton Road, NE Atlanta, GA 30329–4251 Tel: 1–800–ACS–2345 (1–800–227–2345) http://www.cancer.org	Contact your local unit for information about financial resources in your community. Local ACS units should be listed in the white pages of the phone book under "American Cancer Society."
Cancer Care, Inc., National Office 275 Seventh Avenue New York, NY 10001 Tel: 1–800–813–HOPE (1–800–813–4673) Fax: 212–719–0263 http://www.cancercare.org • **AVONcares Program** • **Novartis Program for Men with Cancer** • **Hirshberg Fund** • **Regional/Local Assistance**	Provides financial assistance and relevant education and support to low-income, under- and uninsured, underserved men and women throughout the country in need of diagnostic and/or related services (transportation, childcare, and social support) for a variety of cancers. Details and eligibility vary for each program.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Financial Assistance (continued)

Contact Information	Description
The Leukemia and Lymphoma Society (LLS) 1311 Mamaroneck Avenue White Plains, NY 10605-5221 Tel: 1–800–955–4572 http://www.leukemia-lymphoma.org e-mail: infocenter@leukemia-lymphoma.org	Provides information and financial aid to patients who have leukemia, non-Hodgkin's lymphoma, Hodgkin's disease, or multiple myeloma. Callers may request a booklet describing LLS' Patient Aid Program or the telephone number for their local LLS office. Some publications are available in Spanish.
Hill-Burton Tel: 1–800–638–0742 http://www.hrsa.gov/osp/dfcr/obtain/obtain.htm	The program through which hospitals receive construction funds from the Federal Government. Hospitals that receive Hill-Burton funds are required by law to provide some services to people who cannot afford to pay for their hospitalization. A brochure about the program is available in Spanish.

Tax Deductions

Internal Revenue Service (IRS) Tel: 1–800–829–1040 7:00 a.m. to 10:30 p.m., Monday through Friday http://www.irs.gov	Medical costs not covered by insurance policies can sometimes be deducted from annual income before taxes. Examples of tax-deductible expenses can include mileage for trips to medical appointments and out-of-pocket costs for treatment, prescription drugs, or equipment. The local IRS office, tax consultants, or certified public accountants can determine what medical costs are tax-deductible. These telephone numbers can be found in the local phone book.

Transportation Assistance

Your local unit of the American Cancer Society **Your state or local Department of Social Services** **You hospital social worker**	Nonprofit organizations and some government agencies may arrange free or reduced-cost air transportation for cancer patients traveling to distant cancer treatment centers. Financial need is not always a requirement. To find out about these programs, talk with a hospital social worker.

Transportation Assistance (continued)

Contact Information	Description
American Cancer Society (ACS) 1599 Clifton Road, NE Atlanta, GA 30329-4251 Tel: 1–800–ACS–2345 (1–800–227–2345) http://www.cancer.org	Call to find your local unit. (See page 87 for more information.)
The Leukemia and Lymphoma Society (LLS) 1311 Mamaroneck Avenue White Plains, NY 10605-5221 Tel: 1–800–955–4572 http://www.leukemia-lymphoma.org e-mail: infocenter@leukemia-lymphoma.org	Call to find your local chapter. (See page 95 for more information.)
Eldercare Locator A service of the National Association of Area Agencies on Aging Tel: 1–800–677–1116 Call from 9:00 a.m. to 8:00 p.m., Eastern time	This agency can help coordinate travel for older persons. Also, see agencies on aging (page 99-100).

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Help Paying for Medicines

Contact Information	Description
Cancer Information Service (CIS) Tel: 1–800–4–CANCER (1–800–422–6237) TTY: 1–800–332–8615	Call the CIS to request information about drug companies that assist cancer patients with low incomes.
Pharmaceutical Research and Manufacturers of America (PhRMA) 1100 Fifteenth Street, NW Washington, DC 20005 Tel: 1–800–762–4636 http://www.phrma.org	To make it easier for physicians to identify the growing number of programs available for needy patients, PhRMA created a *Directory of Prescription Drug Patient Assistance Programs.* It lists programs that provide drugs to physicians whose patients could not otherwise afford them. The *Directory* is available on the Web or can be requested over the phone.
Indigent Patient Programs **NeedyMeds** http://www.needymeds.com	Most of the large drug companies have what is called an "Indigent Patient Program." These programs help provide medications to people who cannot afford them. NeedyMeds, an Internet Web site, lists medicine assistance programs available from drug companies. *NOTE: Usually, patients cannot apply directly for these programs. You can ask your doctor, nurse, or social worker to contact them.*
State Prescription Drug Assistance Programs Tel: 1–800–MEDICARE (Medicare Hotline) http://www.medicare.gov	Some states have a pharmaceutical assistance program that will help pay for needed medicines. For a listing of Prescription Drug Assistance Programs in your state, call or visit the Medicare Web site. You can also ask your doctor or social worker about programs for which you may be eligible.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Credit Counseling

Contact Information	Description
National Foundation for Credit Counseling (NFCC) 801 Roeder Road, Suite 900 Silver Spring, MD 20910 Tel: 1–800–388–2227 (National Crisis Hotline) http://www.nfcc.org	NFCC is a national nonprofit network designed to provide assistance to people dealing with stressful financial situations. You can find nonprofit consumer credit counseling services in your area. If you cannot find one in the phone book, the National Foundation for Consumer Credit, Inc., can direct you to a certified consumer credit counselor in your area.

Hospital Payment Plans

Patient Advocate **Financial Aid Counselor** **Social Worker** **Patient Representative (in the Business Office)**	Ask one of these hospital employees about setting up monthly payment plans for hospital bills.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Resources for Specific Groups

The following resources address concerns of specific groups and include information about aging, resources for minority groups, and women's health.

Aging

Contact Information	Description
AARP 601 E St., NW Washington, DC 20049 Tel: 1–800–424–3410 http://www.aarp.org	This organization provides many services, including counseling groups, assistance to the homebound, and benefits and entitlement information.
Administration on Aging (AoA) (US Department of Health and Human Services) 330 Independence Avenue, SW Washington, DC 20201 Tel: 202–619–7501 TTY: 1–800–877–8339 Fax: 202–260–1012 http://www.aoa.gov e-mail: aoainfo@aoa.gov	AoA is the Federal focal point and advocate agency for older persons. Through information and referral and outreach efforts at the community level, AoA seeks to educate older people and their caregivers about the benefits and services available to help them. AoA works closely with its nationwide network of regional offices and state and area agencies on aging to plan, coordinate, and develop community-level services systems that meet their unique needs.
National Association of Area Agencies on Aging 927 15th Street, NW, 6th Floor Washington, DC 20005 Tel: 202–296–8130, Fax: 202–296–8134 http://www.n4a.org **Eldercare Locator (a service of the National Association of Area Agencies on Aging)** Tel: 1–800–677–1116 Call from 9:00 a.m. to 8:00 p.m., Eastern time	The National Association of Area Agencies on Aging (NAAAA) provides Eldercare Locator, a nationwide directory assistance service designed to help older persons and caregivers find local support resources. Eldercare Locator has links to state and local agencies on aging where one can get information about services such as transportation, meals, home care, housing alternatives, legal issues, and social activities.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Aging (continued)

Contact Information	Description
National Institute on Aging (NIA) **(National Institutes of Health)** Building 31, Room 5C27 31 Center Drive, MSC 2292 Bethesda, MD 20892 Tel: 1–800–222–2225 http://www.nih.gov/nia	The National Institute on Aging is involved in research, education, training, information, and referral. This organization provides a broad range of written materials on issues concerning older adults. The NIA also produces *Menopause: One Woman's Story, Every Woman's Story—A Guide for Making Healthy Choices*.

Health Information for Minorities

Cancer Care, Inc., National Office 275 Seventh Avenue New York, NY 10001 Tel: 1–800–813–HOPE (1–800–813–4673) http://www.cancercare.org e-mail: info@cancercare.org	Cancer Care is a national nonprofit agency that offers free support to people with cancer. See page 88 for a description of their services.
Intercultural Cancer Council 1720 Dryden, PMB-C Houston, TX 77030 Tel: 713–798–4617 http://iccnetwork.org e-mail: info@iccnetwork.org	The Council promotes policies, programs, partnerships, and research to address the unequal rates of cancer among minority groups. The Web site provides resources and information on this issue.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Health Information for Minorities (continued)

Contact Information	Description
National Asian Women's Health Organization (NAWHO) 250 Montgomery Street Suite 900 San Francisco, CA 94104 Tel: 415–989–9747 http://www.nawho.org e-mail: nawho@nawho.org	NAWHO is working to improve the health status of Asian women and families through research, education, leadership, and public policy programs. They have resources for Asian women in English, Cantonese, Laotian, Vietnamese, and Korean. Publications on subjects such as reproductive rights, breast and cervical cancer, and tobacco control are available.
Office of Minority Health Resource Center (OMHRC) (a service of the U.S. Department of Health and Human Services' Office of Minority Health) P.O. Box 37337 Washington, DC 20013-7337 Tel: 1–800–444–6472 TDD: 301–230–7199 http://www.omhrc.gov	The Center is one of the nation's largest sources of minority health information. It offers fact sheets, publications, and a newsletter on issues related to minority health. The Center can also refer you to other sources of information.

Women's Health

Contact Information	Description
Office on Women's Health (National Women's Health Information Center) 8550 Arlington Boulevard, Suite 300 Fairfax, VA 22031 Tel: 1–800–994–9662 TTY: 1–888–220–5446 http://www.4women.org	This center offers information on various women's health issues, including body image, nutrition, mammography, pregnancy, and older women's issues.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Other Resources by Topic

Here are some groups that can help you with other questions you might have, including information about such specific topics as alternative medicine, diet, genetic counseling, and rehabilitation.

Complementary and Alternative Medicine

Contact Information	Description
National Center for Complementary and Alternative Medicine (NCCAM)	The Center provides reliable information about the safety and effectiveness of complementary and alternative medicine (CAM) practices.
NCCAM Clearinghouse P.O. Box 7923 Gaithersburg, MD 20898 Tel: 1–888–644–6226 TTY: 1–866–464–3615 http://www.nccam.nih.gov e-mail: info@nccam.nih.gov	The Clearinghouse is the public’s point of contact and access to information about CAM and NCCAM’s programs. Resources are available in English and Spanish.

Consumer Health

Healthfinder (a service of the U.S. Department of Health and Human Services) http://www.healthfinder.gov	The U.S. Department of Health and Human Services’ Healthfinder gives reliable consumer health information. It links to online publications, clearinghouses, databases, Web sites, and support and self-help groups, as well as government agencies and not-for-profit organizations that produce reliable information for the public.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Diet Guides

Contact Information	Description
U.S. Department of Agriculture (USDA) 14th Street and Independence Avenue, SW Washington, DC 20250 *Dietary Guidelines for Americans 2000* Federal Consumer Information Center Tel: 1–888–878–3256 http://www.usda.gov/cnpp/dietary_guidelines.htm	*Dietary Guidelines for Americans 2000* (cost $4.75 + $2.00 S&H) provides details about healthy diets. To order, call the Federal Consumer Information Center. The pamphlet and other information can also be found on the U.S. Department of Agriculture's (USDA) Web site. The Web-based version of the pamphlet is free.

Genetic Counseling

Cancer Genetics Web Site http://www.cancer.gov/cancer_information/prevention **Cancer Genetics Services Directory** http://www.cancer.gov/search/genetics_services Tel: 1–800–4–CANCER	These resources can provide information on cancer genetics or help you locate a cancer genetics counselor.

Rehabilitation

National Rehabilitation Information Center (NARIC) 1010 Wayne Avenue, Suite 800 Silver Spring, MD 20910 Tel: 1–800–346–2742 TTY: 301–495–5626 http://www.naric.com	The Center provides information and referrals to the public and those involved in the care of people with physical or mental disabilities.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Additional Resources

The following groups can offer additional information, such as where to find a support group, more detailed information about specific types of cancer, and various services for cancer survivors and their families.

For a complete list of groups, see the NCI Fact Sheet: *National Organizations That Offer Services to People With Cancer and Their Families* or call 1–800–4–CANCER.

Organization	Description
American Cancer Society (ACS) 1599 Clifton Road, NE Atlanta, GA 30329–4251 Tel: 1–800–ACS–2345 (1–800–227–2345) http://www.cancer.org	Contact your local unit for more information. See page 87 for more information about services.
American Foundation for Urologic Disease (AFUD) 1128 North Charles Street Baltimore, MD 21201 Tel: 1–800–242–2383 http://www.afud.org e-mail: admin@afud.org	The AFUD supports research; provides education to patients, the general public, and health professionals; and offers patient support services for those who have or may be at risk for a urologic disease or disorder. They provide information on urologic disease and dysfunctions, including prostate cancer treatment options, bladder health, and sexual function. They also offer prostate cancer support groups (Prostate Cancer Network). Some Spanish-language publications are available.
American Institute for Cancer Research (AICR) 1759 R Street, NW Washington, DC 20009 Tel: 1–800–843–8114 http://www.aicr.org e-mail: aicrweb@aicr.org	The AICR provides information about cancer prevention, particularly through diet and nutrition. They offer a toll-free nutrition hotline, pen pal support network, and funding of research grants. The AICR also has a wide array of consumer and health professional brochures, plus health aids about diet and nutrition and their link to cancer and cancer prevention. The AICR also offers the AICR CancerResource, an information and resource program for cancer patients. A limited selection of Spanish-language publications is available.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Organization	Description
Cancer Care, Inc., National Office 275 Seventh Avenue New York, NY 10001 Tel: 1–800–813–HOPE (1–800–813–4673) http://www.cancercare.org e-mail: info@cancercare.org	Cancer Care is a national nonprofit agency that offers free support, information, financial assistance, and practical help to people with cancer and their loved ones. Services are provided by oncology social workers and are available in person, over the telephone, and through the agency's Web site. Cancer Care's reach also extends to professionals—providing education, information, and assistance. Some services are available in Spanish.
Cancer Hope Network Suite A Two North Road Chester, NJ 07930 Tel: 1–877–HOPENET (1–877–467–3638) http://www.cancerhopenetwork.org e-mail: info@cancerhopenetwork.org	The Cancer Hope Network provides individual support to cancer patients and their families by matching them with trained volunteers who have undergone and recovered from a similar cancer experience. Such matches are based on the type and stage of cancer, treatments used, side effects experienced, and other factors.
Cancer Information and Counseling Line (CICL) (a service of the AMC Cancer Research Center) 1600 Pierce Street Denver, CO 80214 Tel: 1–800–525–3777 Call from 8:30 a.m. to 5:00 p.m., Mountain time. http://www.amc.org e-mail: cicl@amc.org	The CICL, part of the Psychosocial Program of the AMC Cancer Research Center, is a toll-free telephone service for cancer survivors, their family members and friends, and the general public. Professional counselors provide up-to-date medical information, emotional support through short-term counseling, and resource referrals to callers nationwide.
Gilda's Club, Inc. 322 Eighth Avenue New York, NY 10001 Suite 1402 Tel: 917–305–1200 (call for your local chapter) http://www.gildasclub.org	Gilda's Clubs provide social and emotional support to cancer patients, their families, and friends. Lectures, workshops, networking groups, special events, and a children's program are available.

Organization	Description
Lance Armstrong Foundation P.O. Box 161150 Austin, TX 78716–1150 Tel: 512–236–8820 http://www.laf.org	The Lance Armstrong Foundation (LAF) seeks to enhance the quality of life for those living with, through, and beyond cancer. Founded in 1997 by cancer survivor and champion cyclist Lance Armstrong, the LAF's mission is to enhance the quality of survival for those diagnosed with cancer. LAF seeks to promote the optimal physical, psychological, and social care and recovery of cancer survivors and their loved ones. The Foundation focuses its activities on the following areas: survivor services and support, groundbreaking survivorship programs, and medical and scientific research grants.
National Coalition for Cancer Survivorship (NCCS) 1010 Wayne Avenue Suite 770 Silver Spring, MD 20910–5600 Tel: 1–877–NCCS YES (1–877–622–7937) http://www.cansearch.org e-mail: info@cansearch.org **To order the *Cancer Survival Toolbox,* call:** Tel: 1–877–TOOLS–4–U (1–877–866–5748) http://www.cansearch.org/programs	NCCS is a network of groups and individuals offering support to cancer survivors and their loved ones. It provides information and resources on cancer support, advocacy, and quality-of-life issues. A section of the NCCS Web site and a limited selection of publications are available in Spanish. Offerings include a free audio program that teaches cancer survivorship skills, the *Cancer Survival Toolbox*.
National Lymphedema Network (NLN) 1611 Telegraph Avenue Suite 1111 Oakland, CA 94612–2138 Tel: 1–800–541–3259 http://www.lymphnet.org e-mail: nln@lymphnet.org	The NLN provides education and guidance to lymphedema patients, health care professionals, and the general public by providing information on the prevention and management of primary and secondary lymphedema. The Network provides a toll-free support hotline; a referral service to lymphedema treatment centers and health care professionals; a newsletter; and a computer database. Some Spanish-language materials are available.

There may be a charge for publications listed in this guide. Ask if there is a cost when ordering.

Organization	Description
Patient Advocate Foundation (PAF) 753 Thimble Shoals Boulevard, Suite B Newport News, VA 23606 Tel: 1–800–532–5274 http://www.patientadvocate.org e-mail: help@patientadvocate.org	The PAF provides education, legal counseling, and referrals to cancer patients and survivors concerning managed care, insurance, financial issues, job discrimination, and debt crisis matters.
R. A. Bloch Cancer Foundation, Inc. 4435 Main Street Suite 500 Kansas City, MO 64111 Tel: 1–816–WE–BUILD (816–932–8453) http://www.blochcancer.org e-mail: hotline@hrblock.com	The R. A. Bloch Cancer Foundation matches newly diagnosed cancer patients with trained, home-based volunteers who have been treated for the same type of cancer. They also distribute informational materials, including a multidisciplinary list of institutions that offer second opinions. Information is available in Spanish.
United Ostomy Association 19772 MacArthur Boulevard, Suite 200 Irvine, CA 92612–2405 Tel: 1–800–826–0826 (6:30 a.m. to 4:30 p.m., Pacific time) http://www.uoa.org e-mail:uoa@deltanet.com	The United Ostomy Association helps ostomy patients through mutual aid and emotional support. It provides information to patients and the public and sends volunteers to visit with new ostomy patients.
The Leukemia and Lymphoma Society (LLS) 1311 Mamaroneck Avenue White Plains, NY 10605-5221 Tel: 1–800–955–4572 http://www.leukemia-lymphoma.org e-mail: infocenter@leukemia-lymphoma.org	The goal of LLS is to find cures for leukemia, lymphoma, Hodgkin's disease, and multiple myeloma and to improve the quality of life of patients and their families. LLS supports medical research and provides health education materials and services for patients and families.
The Wellness Community (National) 35 East Seventh Street, Suite 412 Cincinnati, OH 45202 Tel: 1–888–793–WELL (1–888–793–9355) http://www.wellness-community.org e-mail: help@wellness-community.org	The Wellness Community provides free psychological and emotional support to cancer patients and their families. They offer support groups facilitated by licensed therapists, stress reduction and cancer education workshops, nutrition guidance, exercise sessions, and social events.

Glossary

alternative medicine: Healing approaches and therapies used *in place of* traditional treatments prescribed by a medical doctor. Some examples are vitamins and herbs, special diets, spiritual practices, and acupuncture.

anxiety: Usually mild, brief fear caused by a stressful event. Anxiety can be very serious if it continues over long periods of time, leading to anxiety disorder, which should be treated by a professional.

cancer survivor: A term used to describe a person with cancer, from the time he or she is diagnosed through the balance of his or her life.

chemotherapy (kee-mo-THER-a-pee): A cancer treatment using anticancer drugs.

clinical trial: A research study to find better ways to prevent, detect, and treat cancer and to improve care for people with cancer.

complementary medicine: Healing approaches and therapies used *in addition to* traditional treatments prescribed by a medical doctor. Some examples are vitamins and herbs, special diets, spiritual practices, and acupuncture.

depression: Having a depressed or low mood for most of the day and on most days. A person may no longer enjoy life or normal activities; have changes in eating and sleeping habits; and feel nervous, rundown, and tired. A person may also feel worthless or guilty, have trouble concentrating, and think about death or suicide all the time. If you experience any of these signs of depression for more than 2 weeks, talk to your doctor about treatment.

endoscopy (en-DAHS-ko-pee): The use of a thin, lighted tube (called an endoscope) to look at the inside of the body.

fatigue: A lack of energy or a feeling of being tired, weak, or worn out that can cause stress and decrease a person's ability to function normally.

follow-up care: Seeing a doctor for regular checkups following cancer treatment.

genetic counseling: Counseling from a specially trained person about the chance that other people in a cancer survivor's family will get cancer. Advice from a counselor can help families understand their chances of getting cancer and make important decisions about prevention.

imaging procedures: Ways of taking pictures of areas inside the body.

impotent (IM-po-tent): When a man's penis is unable to become erect.

lymphedema (LIMF-eh-DEE-ma): Swelling in the arms and legs caused by a buildup of fluid in the body tissues. It may happen after surgery or radiation to remove lymph nodes in the underarm or groin.

metastasis (meh-TAS-ta-sis): The spread of cancer from one part of the body to another. Cancer is said to have metastasized when tumors form from cells like those in the original (primary) tumor and spread (secondary tumors) to other parts of the body.

oncologist (on-KOL-o-jist): A doctor who is an expert in cancer treatment.

ostomy (AHS-tuh-mee): An operation to create an opening (stoma) from an area inside the body to the outside. Some types of ostomy are colostomy (an opening into the colon from the outside of the body, making a new way for waste to leave the body) and urostomy (an opening from inside the body to the outside, making a new way for urine to leave the body).

recurrence: The return of cancer. Cancer is said to have recurred when it returns to the same body part as the original (primary) tumor or in another location after the original tumor has disappeared.

supportive care: Treatment to prevent, control, or decrease side effects from cancer and to improve the comfort and lives of people who have cancer.

survivor (see cancer survivor)

wellness plan: A plan created by a doctor and a patient to help the patient take care of his or her own health after cancer treatment.

Organization Guidelines for Follow-up Care

The following organizations have guidelines for follow-up care for some cancers. You can use these guidelines when you talk with your doctor or other health care providers. These guidelines are not meant to contradict or take the place of your provider's knowledge or judgment.

American Society of Clinical Oncology (ASCO)
1900 Duke Street, Suite 200
Alexandria, VA 22314
1–888–651–3038 or 703–299–0150
www.asco.org
(Guidelines for breast and colorectal cancer)

National Comprehensive Cancer Network
50 Huntington Pike, Suite 200
Rockledge, PA 19046
1–888–909–NCCN (6226)
www.NCCN.org
(Guidelines for prostate, ovarian, neuroendocrine, hepatocellular, gall bladder, thyroid, bone, skin, colon and rectal cancers; breast cancer *in situ*; melanoma; cholangiocarcinoma; and adult AML)

The University of Texas M.D. Anderson Cancer Center
1515 Holcombe Blvd.
Houston, TX 77030
1–800–392–1611 or 713–792–6161
www.mdanderson.org
(Guidelines for breast, cervical, epithelial ovarian, colon, rectal, laryngeal, tongue, renal cell, bladder, and prostate cancers, as well as bone sarcoma, soft tissue sarcoma, and melanoma *in situ*)

The Cancer Survivors' Bill of Rights

(Excerpts from the National Coalition of Cancer Survivorship's Cancer Survivors' Bill of Rights. NOTE: This is not a national law.)

The National Coalition for Cancer Survivorship presents this new version of the Survivors' Bill of Rights to call public attention to survivor needs, to enhance the quality of cancer care, to empower cancer survivors, and at the same time bring greater satisfaction to them and their physicians, employers, families, and friends.

1. Survivors have the right to continuous lifelong medical care, as needed. The physicians and other professionals involved should make every effort to be:
    - Sensitive to cancer survivors' lifestyle choices and their need for self-esteem, dignity and privacy of the information trusted to them;
    - Careful, no matter how long these patients have survived, to take symptoms seriously and not to dismiss aches and pains, for fear of recurrence is a normal part of survivorship;
    - Vigilant to watch for any long-term and late effects of cancer and its treatment in follow-up clinics and offices;
    - Informative and open, providing survivors with as much or as little candid medical information as they wish, and encouraging informed participation but not expecting survivors to manage that care on their own;
    - Knowledgeable about counseling and rehabilitation resources, and willing to refer survivors and their families as appropriate for emotional support and therapy aiming to improve the texture as well as the quantity of time that is theirs to live.
2. No matter in which setting their care is offered—be it fee-for-service or some sort of managed care system—survivors have the right to quality care emphasizing:

- Informed choice—choice of the setting in which care is delivered, choice of primary physicians and specialists delivering that care, as well as choice of appropriate, effective and safe treatments (including ongoing clinical trials);
- Efficient yet humane management of such unfortunate by-products of disease as fatigue and pain—pain control management, for example, which approaches survivors more as partners in identifying the proper amount of medication needed at any given time than as potential drug addicts;
- Appropriate use of hospital and other facilities, wherein cost effectiveness and patient-centered care are balanced so that no survivor is dismissed—after a mastectomy, for example—unable to care for her or himself or secure the care needed to avoid dangerous and painful situations;
- Constant respect for survivors' wishes as to when and how to discontinue treatment should that time arise, including the scrupulous honoring of "living wills" and similar documents.

3. In their personal lives, survivors, like other Americans, have the right to the pursuit of happiness. This means they have the right:

   - To talk with their families and friends about their cancer experience if they wish, but to refuse to discuss it if that is their choice, and not to be expected to be more upbeat or less blue than anyone else;
   - To be free of the stigma of cancer as a "dread disease" in all social relations, wherever they may take place—from home to work or market-place;
   - To be free of blame for having the disease and of guilt for having survived it;
   - To participate in support groups and other survivor support and/or advocacy activities as they wish, for in such settings they usually feel less isolated, more informed, and more able to express their feelings, be they feelings of hope or of despair, without fear of being regarded as "bad" or "ungrateful" or simply "uncooperative" patients.

4. In the work place, survivors have the right to equal job opportunities. This means they have the right:
    - To aspire to jobs worthy of their skills, and for which they are trained and experienced, and thus not to have to accept jobs they would not have considered before their cancer experience;
    - To be hired, promoted, and accepted on return to work, according to their individual abilities and qualifications, and not according to "cancer" or "disability" stereotypes with "reasonable accommodation," under federal and state law, such as changes in duties or hours, which allows them to work while receiving medical treatment without falling into a survivors' "Catch-22"—too ill to work, but too healthy to qualify as "disabled" and so entitled to protection under the Americans with Disabilities Act;
    - To privacy about their medical histories.
5. Since health insurance is an urgent survivorship concern, every effort should be made to assure all survivors decent affordable coverage, whether public or private, or provided under managed care or fee-for-service systems. This means:
    - For employers, that survivors have the right to be included in group health coverage … regardless of health history
    - For physicians, counselors, and other professionals concerned, that they keep themselves and their survivor-clients informed and up-to-date on the dangers of health insurance discrimination …
    - For social policy makers, both in government and in the private sector, that they seek both to broaden insurance programs to include diagnostic procedures and treatments which help prevent recurrence and ease survivor anxiety and pain, as well as to lower the unfair barriers often imposed by the accidents of race, minority culture, age, or plain lack of means to pay for adequate health insurance coverage.

In sum, cancer survivors have the overriding right to access quality health care. Implicit in that right is universal access to adequate health insurance coverage. For “quality” becomes an empty word without the means to achieve such coverage. A cancer may not even be discovered. And if it is, care may be sub-optimal, no one will be accountable for it, and the whole society will be the losers.

Patient Notes/Follow-up Care Guide

Doctor's Name:
Type:
Address:
Phone:
Nurse's Name:

Questions:

Appointment Dates:

Doctor's Name:
Type:
Address:
Phone:
Nurse's Name:

Questions:

Appointment Dates:

Doctor's Name: ______________________

Type: ______________________

Address: ______________________

Phone: ______________________

Nurse's Name: ______________________

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Questions: ______________________

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Appointment Dates:

______________________ ______________________ ______________________

______________________ ______________________ ______________________

______________________ ______________________ ______________________

Pharmacy Name: ______________________

Pharmacist's Name ______________________

Address: ______________________

Phone: ______________________

Questions: ______________________

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Social Worker/Therapist: ______________________

Type: ______________________

Address: ______________________

Phone: ______________________

Questions: ______________________

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Appointment Dates:

______________________ ______________________ ______________________

______________________ ______________________ ______________________

______________________ ______________________ ______________________

Questions for the Follow-up Plan

	3 Months	6 Months	1 Year
1. How often should I see the doctor for a routine visit?	☑ Dr. Smith (Mar)	☐ Dr. Chu (Jun)	☐ Dr. Smith
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐

2. What follow-up tests, if any, should be done? How often?

☐ Blood tests (Jan)
☐
☐
☐
☐
☐

3. Are there symptoms I should watch for?

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

At each visit, tell your doctor/ health care team about:

- Symptoms that you think may be a sign of cancer’s return
- Any pain that troubles you
- Any physical problems that get in the way of your daily life or that bother you, such as fatigue, trouble sleeping, loss of sex drive, weight gain or loss
- Any medicines, vitamins, or herbs you are taking and any other treatments you are using
- Any emotional problems you may have; any anxiety or depression you have had in the past

- Any changes in your family medical history
- Things you want to know more about

Kinds of medical records and information you should keep

- Specific type of cancer
- Date(s) of cancer diagnosis
- Details of all cancer treatment, including the places and dates where treatment was received
- Contact information for all doctors and other health professionals involved in treatment and follow-up care
- Complications that occurred after treatment
- Information on *any* other kind of supportive care you had (such as pain or nausea medication, emotional support, nutritional supplements, etc.)

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) see scale	Pain medication (name, dose, how often taken)	Other pain-relief methods tried	Side effects from pain medication
June 6 (Example)	8 am	6	Morphine 30 mg every 4 hrs	massage	constipation

Practicing Relaxation to Relieve Pain or Stress

Many people with cancer have found that practicing deep relaxation has helped relieve their pain or reduced 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.

Relaxation Skills

Before trying the full exercise below, first practice steps 1 through 5, so you can get used to deep breathing and muscle relaxation.

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.** Clench your teeth and 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 buttocks together.
   - **Thighs.** Press thighs together.
   - **Calves.** Point your toes up, toward your knees.
   - **Feet.** Point your toes down, like a ballet dancer's.

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.

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.

Keep in Mind

These exercises don’t work right away for everyone. It can take some time to feel these exercises are working, so practicing may help. If any of these steps makes you feel uncomfortable, feel free to leave it out. Ask your doctor or nurse about other ways to relax if these exercises don’t work for you.

Notes

Tell Us What You Think…

To order more copies of this booklet, call **1–800–4–CANCER.**

Look for other booklets in the Facing Forward Survivor Series…

Available in Spring 2002:

- ***Siga adelante: la vida después del tratamiento del cáncer***
- ***Ways You Can Make a Difference in Cancer***

Available in 2003:

- **Guides for health professionals and family members**

Please tell us what you think about this booklet.

1. This booklet was:

☐ easy to understand ☐ hard to understand

2. This information was:

☐ too much ☐ too little ☐ just about right

3. I suggest adding/deleting information about:

____

____

____

4. I would …

____ recommend this booklet to another person
____ not recommend this booklet to another person

5. I received this booklet from:

____ a doctor, a nurse, or other health professional
____ an information rack at a cancer center, health clinic, hospital, doctor's office
____ the National Cancer Institute's Cancer Information Service at 1–800–4–CANCER (1–800–422–6237)
____ a family member or friend
____ other (please explain):______________________________

6. I am: ☐ a cancer survivor ☐ a family member or friend ☐ a health professional ☐ other_______________

7. What is your age? ______

8. Does this booklet help you:

a) get the information that you need?	☐ yes ☐ no
b) understand more about issues related to:	
follow-up medical care	☐ yes ☐ no
your body	☐ yes ☐ no
your mind and feelings	☐ yes ☐ no
your social relationships	☐ yes ☐ no
c) find resources or support in your community?	☐ yes ☐ no
d) feel your experience is like that of other survivors?	☐ yes ☐ no
e) feel more in control of your health?	☐ yes ☐ no

Thank you very much for your feedback.

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6116 Executive Blvd., Suite 202, MSC–9692
Bethesda, MD 20814–9692

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Masterfile: front cover - middle two photos, i; icon, - iv; 1 - lower right; 2 - upper left, 8, 12, 26, 27, 42, “Your Mind and Your Feelings After Cancer Treatment” divider page,second from top; 48 - upper left; 59 - upper left and lower right, 64 - upper left and lower right “Your Social Relationships After Cancer Treatment” divider page - second from top; 71, 73, “Practical Matters After Cancer Treatment” middle and lower right.

NCI: iii, “Getting Medical Care After Cancer Treatment” divider page, lower right; 6 - upper left, 11, “Your Body After Cancer Treatment” second from top; 33, 37, 38, 52, 61 - lower right, 75 - upper right; 77, 121.

PhotoDisc: 1; 10 - lower right; “Your Body After Cancer Treatment” divider page, bottom right; 42, “Your Mind and Your Feelings After Cancer Treatment” divider page, second from bottom; 47, 48 - lower right; 57 - upper left; 62, “Your Social Relationships After Cancer Treatment” divider page, 72 - upper left; 75, lower right, 78, 85 - upper left and middle

Texas Genetics Consortium, Houston, TX.: front cover - bottom right; 20, 72 - lower right; 85 lower middle

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Disclaimer:

The quotes in this booklet are from actual cancer survivors contacted by the National Cancer Institute. To protect confidentiality, their names were changed. The photographs in this book were supplied by the NCI or purchased from commercial sources and may not necessarily be of actual cancer survivors. The photographs were included to put a “human face” on the cancer experience.

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