Facing Forward Series

Ways You Can Make a Difference in Cancer

U.S. DEPARTMENT OF
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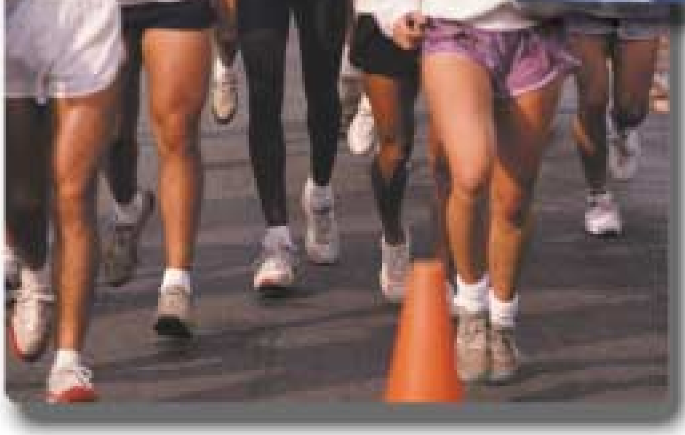


This book is given to you by

Contents

Giving back has helped my recovery … I was able to get involved and get moving. When I'm helping others, I don't have time to think about myself or to have any self-pity, because I'm too busy.

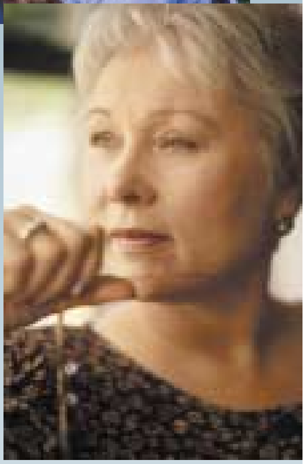
"I started out as a volunteer with a local breast cancer project in my hometown. Women who had survived breast cancer were going around to churches telling their stories. I heard about what those women were doing after I had completed treatment for my second cancer. I was starting to get back on my feet and thinking differently about my life. The first time I got breast cancer, at age 35, I went on with life as usual—raised my children, sent them to college, planned their weddings. But after the second diagnosis, 20 years later, it hit me that: *'Hey! You're a breast cancer survivor, and you can do something.'* So I started helping other people.

I was very excited about going into the churches because I was brought up in the church, and it was something I felt I could do. Right away, it became a passion for me. I loved the results I got: Women became more aware of breast cancer and were less frightened about it. Anytime you can see that you are making a difference, it is something that keeps you going.

Giving back has helped my recovery. From personal experience, I can say that helping others helps you. It is therapy. It gave me something to do and took my mind off what I was going through. I was able to get involved and get moving. When I'm helping others, I don't have time to think about myself or to have any self-pity, because I'm just too busy. And it helped me to learn more about my own health.

I think my greatest reward is that I have made so many wonderful friends, and that has been valuable to my recovery. My life is richer because I have had the opportunity to help others. I have met so many men and women who have enriched my life and have given me the encouragement to keep on going. I know that there is a purpose and a design to what I have gone through."

Mattye, two-time breast cancer survivor, 62



About This Book

Many people want to make a difference in cancer. They may want to learn how to help their neighbors, join an educational group, run in a race, or be part of group that makes decisions about cancer research or programs.

The National Cancer Institute (NCI) has written this book as a way to help cancer survivors get involved in activities like these. This book is also a tool organizations can use to help people who ask, "What can I do to fight cancer?"

Whether you have cancer or know someone who does, this book has many ideas about ways you can get started in making a difference.

This book is written for people who are:

- Newly diagnosed with cancer.
- In treatment now or finished with treatment.
- Living with cancer as a long-term illness.
- Having a recurrence of cancer (whose cancer has returned).
- Family members or friends of someone with cancer or someone who had cancer.
- At high risk for getting cancer.

This book includes information to help you:

- **Learn what it is like to make a difference in the fight against cancer.** The book has many stories about people who are involved in cancer-related activities. We hope these stories will interest and inspire you.
- **Decide if you want to "get involved" and volunteer to help others.** Some people are ready right now; others may never be. You need to decide if the time is right for you to get involved.

- **Choose activities that interest you.** The Guide on page 15 can help you find cancer-related activities you might like to do. The Guide also has ideas about ways you can put your interests, talents, and skills to good use.
- **Learn about cancer organizations.** The resource section at the back of this book has information about cancer organizations across the country. It includes phone numbers, addresses, and Web sites for many of these groups.

Read this book when the time is right for you. You might want to:

- **Read only the chapters that interest you.** Some of the chapters may interest you more than others. Read the ones that have meaning for you now. As your needs and interests change, you can go back and read the chapters you skipped before.
- **Share this book with a friend or family member.** People who know someone with cancer, as well as those who have cancer, may want to learn how they can make a difference and get involved.
- **Save this book for another time.** You may not be ready, interested, or able to get involved right now. That's okay. Save this book for another time or give it to someone else who wants to know more about cancer-related activities.

Terms used in this book

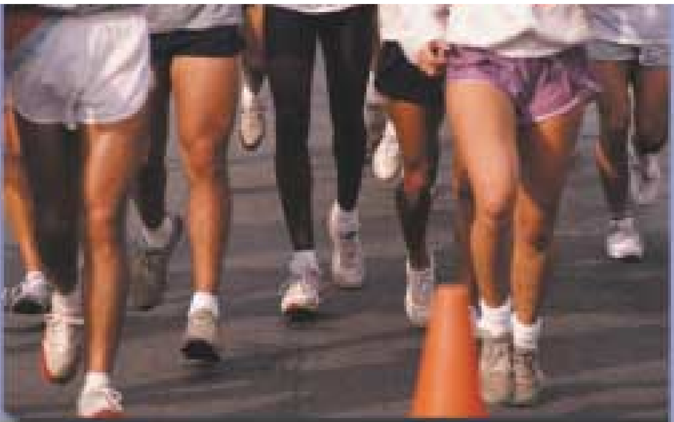
Cancer survivor is used throughout this book. We use the term to describe someone who is recovering or has recovered from cancer. Survivors can also be family members or caretakers of people treated for cancer. Not everyone likes the term *survivor*, but we use it to help people think about their lives as more than just a cancer diagnosis.

Cancer-related activity refers to any activity that helps others in their cancer experience. A cancer-related activity can be a one-time event, like talking on the phone to someone who has cancer. It can also be a more long-term activity, like planning a cancer awareness program where you live.

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

? means that this section discusses questions that might come up and possible solutions to them.

means that this section has helpful hints about how to get started with a cancer-related activity.



Making a Difference

What it Means

Making a Difference: How You Can Benefit

"When I was diagnosed, it was a frightening, lonely time. Everything changed when I found others who were fighting the same disease. Once I had the information I needed and my situation was under control, I decided to help others."

Steve, myeloma survivor, 48

Cancer survivors and those who are close to them, as well as people who have lost someone to cancer, know what it is like to live with cancer. Getting involved in cancer-related activities is like a two-way street. When you help others, you also help yourself. Here are some benefits of getting involved in cancer-related activities:

- **You accept cancer as part of your life.** When you get involved, cancer can give a new meaning to your life. *"Now that I am a cancer survivor, my life will go on, but it has changed. I need to make my cancer experience mean something,"* said one 42-year-old survivor.
- **You are less afraid of cancer.** People often find that the more they know about cancer, the less they fear it.
- **You may feel more spiritual.** As one survivor said, *"I am fulfilling a promise that I made to God."*
- **You feel that you are doing something useful with your cancer experience.** As one person said, *"Getting involved is a powerful force in my life because I am doing something to make the world better."*

- **You have more confidence.** People often feel better when they work with others toward a common goal. As one survivor said, *"I'm not a victim anymore."*
- **You meet other people who share the same kind of experiences**. *"Only another survivor can tell how it is and sympathize with a person and offer support and advice,"* said a 36-year-old survivor.
- **You make a difference in other people's lives.** People can feel good when they make a difference in the lives of others.
- **You teach others about cancer.** This includes talking with people about what it means to have cancer as well helping someone through it. As a father who lost a child to leukemia said, *"It is not just about me and my daughter. It is about all the moms and dads who have to go through this painful experience with their kids. We know what it is like to be afraid, feel guilty, and not know where to turn. I will keep on working for these kids and their parents to make sure that their needs are met."*
- **You find meaning in the face of a life-threatening illness.** Research has shown that cancer survivors often find new meaning in their lives when they get involved. This can be an important part of the healing process. Research has also shown that people who feel a part of their community enjoy better health and feel a sense of purpose in their lives.

Things to Think About

"My cancer treatment was years ago. At first, I wanted nothing to do with cancer. I wouldn't even read a magazine that had an article about cancer. Now, I am ready, and I want to do something with my cancer experience."

Frieda, uterine cancer survivor, 72

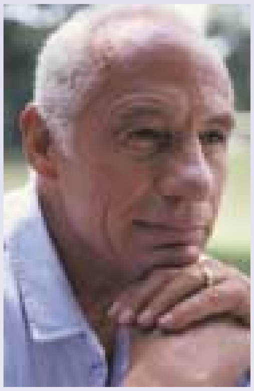
People with cancer, as well as those who love and care about them, may want to get involved in cancer-related activities. But it is important to ask, "Is this the right time to get involved?"

The answer to this question will be different for each person, since everyone has his or her own experience with cancer. As you decide if this is the right time for you, think about how long you've been dealing with cancer, your health, your feelings, and your comfort in talking about cancer.

Think About How Long You've Been Dealing With Cancer

If you are reading this book, you may be:

- **In treatment now, or recently finished with your cancer treatment.** Some people find that getting involved helps them think about things other than cancer. Some even say that it makes their treatment seem easier. Other people find that treatment keeps them too busy or leaves them too tired to get involved.
- **Living with advanced cancer.** Some people living with advanced cancer feel that getting involved is a good way to care for the people they will leave behind. They want to make a difference and help others right up to the end of their lives. Think about how you feel, and decide if you have the health and strength to get involved now.
- **At high risk for getting cancer.** You may have a strong family history of cancer and may be at risk for getting the disease yourself. This can be hard to accept. Some people find that getting involved in cancer-related activities is a way to help themselves as well as others.
- **A family member or friend of someone with cancer.** You know what it is like to care for someone who has cancer. Getting involved in volunteer activities is a good way for some people to give and get the support they need, but it can also be hard. Think about whether getting involved in cancer-related activities is right for you.
- **Someone who has lost a family member or friend to cancer.** You may still be sad and grieving after someone you care about dies of cancer. Getting involved can be a way for many people to do something positive with these feelings.



Think About Your Health

Think about your own health needs before you decide to get involved. Decide if you have enough energy or time to start a new project. Some people want to wait until their health is better. Others choose an activity that is easy for them now.

Think About Your Feelings

People often think about their own experience when they get involved in a cancer-related activity. This is good for some people as it can help them deal with their own feelings. This can also be hard. Sometimes people become upset when they get involved in cancer-related activities.

Take some time to think about your feelings. If you are very worried, angry, or depressed right now, you might want to talk with a counselor about your feelings. Later, when you feel more positive, you can begin to think about ways to help others.

Think About Your Comfort in Talking About Cancer

You can still get involved in cancer-related activities, even if you do not want to talk about your own experience. If this is how you feel, find activities in which you do not have to share your personal feelings or thoughts.

What if "getting involved" is a constant reminder of how hard cancer is for me?

Getting involved in cancer-related activities can remind you of your own experience. This can be good, as it may help you with your own issues while you help others with theirs. Getting involved can also be hard. If you find you are not ready right now, take the time you need to help yourself before you offer to help others.

Think About What You Can Give

Many people are very busy and don't have a lot of time to give to cancer-related activities, but there are still ways they can help others. For example, you can donate money, books, or clothing that other people need for their cancer care.

Think About Where You Live

Some people, especially those who live in rural areas, find that there are no cancer-related activities nearby. If this happens, you might have to think about other ways to get involved. You can, for example, start a new activity or travel to one that is far away. You might also want to get involved at a distance by phone, mail, or over the Internet.

Think About What You Like to Do With Your Time

Everyone has an interest or skill that can help others. As you decide how to get involved, think about your talents, interests, and lifestyle. This includes your culture, religion, and even your hobbies. You may also want to think about what you like and don't like, as well as subjects you want to learn more about.

> *"Whenever somebody says to me, 'I could never get up in front of thousands of people and speak like you do,' I always say, 'You don't have to.'"*
>
> Margaret, cervical cancer survivor, 42

Here are some examples of talents or skills that many people have used to make a difference in cancer.

Skill or talent	What you like to do
Listening	Help people tell their stories and express their concerns. You also answer questions without giving your opinion or passing judgment.
Support	Help others by offering to do errands, baby-sit, or drive them to appointments.
Enthusiasm	Motivate others and give them ideas about how to get things done.
Creativity	Come up with new ideas or use your talents, such as quilting, selling homemade desserts, or developing a public relations campaign.
Learning and teaching	Learn new information and teach others what you know.
Communication	Write. You can get your ideas across by writing articles or speaking in public.

Skill or talent	What you like to do
Group work	Work with others and be part of a team that gets things done.
Office skills	Use the computer, talk on the phone, and organize records and files.
Organizational skills	Plan meetings, events, or group activities, (like organizing a phone call alert list or "tree," planning a fundraiser, or starting a local support group).
Leadership skills	Take charge and get things done. Get people to work together on an activity.

Even if you're not sure about your skills or talents, the Guide on page 15 can help you match your skills and experiences with cancer-related activities. Use the Guide to find the types of activities that interest and inspire you.

Finding Ways You Can Make a Difference:

A Guide

You've decided to make a difference in cancer. Now, your work is to find activities you like to do and that match your interests.

Use this Guide as a way to find activities that interest you. There are no right or wrong answers; simply put a checkmark next to the statements that describe you.

Answer all the questions first. If you have two or more checkmarks in one section, you may want to take a look at the pages it directs you to. Reading these pages can give you some ideas about ways you can make a difference.

Directions: Put a checkmark (✔) next to each statement that describes you.

Thinking about Yourself

- ☐ I need to talk about my problems with other people.
- ☐ I feel lonely and want to talk with others who understand what I've been through.
- ☐ I want to learn new information about cancer.
- ☐ I want to know about and protect my rights as a cancer survivor.
- ☐ I am unhappy with my health care situation and want to make it better.

If you have two or more ✔s in this section, you might want to help yourself (or someone close to you) before you help others, even if you have ✔s in other sections. You might also want to take some time to learn more about your type of cancer. (See pages 79-93 for more information.)

Helping Others

- ☐ I like to meet new people.
- ☐ I am good at listening to others.
- ☐ I like to talk with others about cancer information.
- ☐ I want to help people who are struggling with cancer.
- ☐ People helped me/us during treatment, and I now want to do the same for others.

If you have two or more ✔s in this section, you may want to help others who are dealing with cancer. Think about whether you want to help people on your own or work with a cancer-related organization. (For more information, go to the tab: *Cancer-Related Organizations.*)

Learning and Teaching

☐ People should learn more about cancer, and I would like to teach them.

☐ I like to talk with people—even people I don't know.

☐ I like to speak in front of large groups of people.

☐ I enjoy talking about issues that are important to me, like cancer screening or support for people with cancer.

If you have two or more ✓s in this section, you may want to increase awareness and teach others about cancer. Think about whether you want to help people on your own or work with a cancer-related organization. (For more information, go to the tab: *Cancer-Related Organizations.*)

Working on Cancer-Related Events

☐ I like working with people and being part of large events.

☐ I would like to help with a local event—near where I live or work.

☐ I want to get involved, but only have time to help once in a while.

☐ I am comfortable asking people to donate to cancer-related causes.

☐ I am interested in giving money, computers, or other items to a cancer-related cause.

If you have two or more ✓s in this section, working on fundraising or awareness events may be a good way for you to get involved. Think about whether you want to help people on your own or work with a cancer-related organization. (For more information, go to the tab: *Cancer-Related Organizations.*)

Working in Advocacy

☐ I want to help change the health care system for others with cancer.

☐ I want to see changes in laws and policies related to cancer.

☐ I like the idea of talking to elected officials about cancer issues.

☐ I like to share my ideas with others through phone calls, letters, or e-mails.

☐ I want to be part of a network that can alert me about important cancer issues.

If you have two or more ✓s in this section, you may be interested in getting involved with a specific cause, idea, or policy related to cancer. This work is usually done with a cancer-related organization. (For more information, go to the tab: Cancer-Related Organizations.)

Working in Research

☐ I find science very interesting.

☐ I may be interested in taking part in a research study or clinical trial.

☐ I want to let others know about research studies and clinical trials.

☐ I want to help make decisions about cancer research.

☐ I like the idea of talking with scientists about my opinions on cancer.

If you have two or more ✓s in this section, you may be interested in participating in research or encouraging others to do so. (For more information, go to the tab: *Cancer Research.*)

Working in Government Programs

☐ I want to work on programs that help people with cancer.

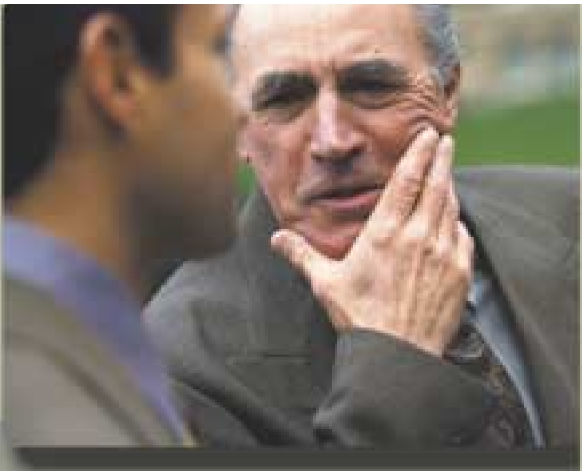
☐ I want to share my ideas about ways to help people with cancer.

☐ I would like to help more people get screened for cancer.

☐ I think I would be comfortable talking about cancer with scientists and public officials.

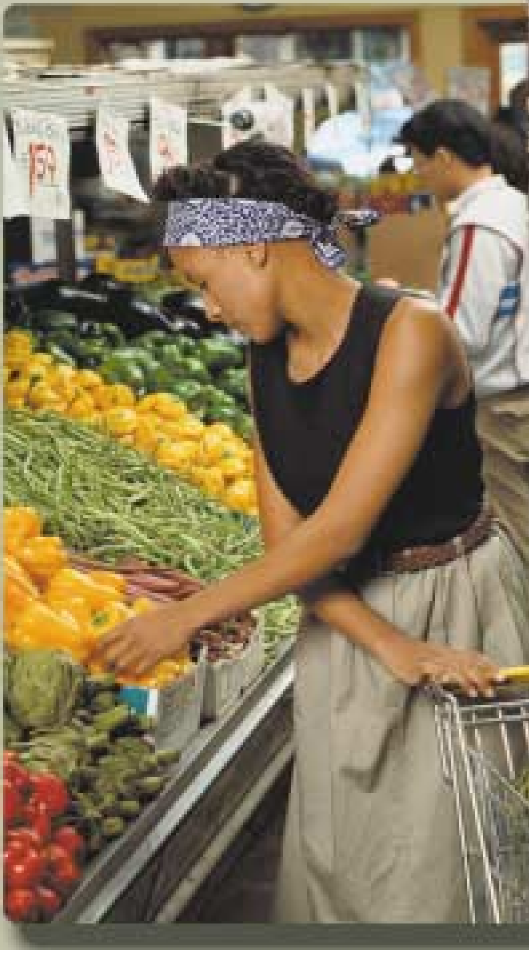
☐ I would like to know how new medicines and treatments are developed and approved.

If you have two or more ✓s in this section, you might want to get involved in government programs. (For more information, go to the tab: *Government Programs and Policies.*)



Making a Difference

In Everyday Ways



***All you need to help others is passion and caring …
Even a short conversation can help save a person's life.***

"When I was diagnosed 16 years ago, I was scared. I thought cancer was a death sentence. So I decided that if I survived, each day I would tell at least one person with cancer that fear is the enemy and education is the path to survival. I set up two support groups at a local hospital. There are a lot of myths that people believe but aren't true …. I wanted to educate people so they can move from 'victim' to 'victor.' And I also did my own learning, keeping up with the latest news about breast cancer treatments.

All you need to help others is passion and caring. Even though people think you have to live in a big city like New York or Chicago, you can be in a small town and tell the people who live near you where to get the information they need. Even a short conversation can help save a person's life.

I've gotten back much more than I've given. I've met some of the most courageous and caring people in the world. Cancer has been a positive force in my life. It's given me a chance to make a difference in the world. It's not always easy, but I have the courage to keep on because I know that others need me."

Bobbi, breast and thyroid cancer survivor, 66

About Making a Difference in Everyday Ways

There are many ways you can make a difference in the lives of others. This chapter looks at how you can make a difference in everyday ways, like helping someone with household chores, learning and teaching, sharing your experiences, or helping others through the health care system.

Helping With Everyday Activities

You can make a big difference by helping in small ways. This includes everyday activities such as chores and errands. For example, you can:

- Bring a meal, do an errand, or mow someone's lawn without being asked.
- Help people with their grocery shopping or household chores, or offer to baby-sit or take care of their pets.
- Drive people to their doctors' appointments. This can be a big help, especially when people have to travel a long distance.
- Arrange meals for someone who is sick. *"We decided to help organize meals after our neighbor got five pans of lasagna in one day,"* said a friend of someone with colon cancer.
- Do small things for others that you would have liked people to do for you, like taking the kids out for a day or renting some videos.
- Let people know how they can learn more about cancer. For example, you can tell them about the National Cancer Institute or a local cancer organization. Many of these groups are listed at the back of this book. (See pages 71-93 for more information.)

What if I find that I talk too much about myself?

If you find that you are thinking and talking too much about yourself and not enough about others, you may not be ready to get involved right now. People need time to deal with their feelings and make sense of their cancer experience. You may want to get help for yourself and talk with a counselor about your feelings and concerns.

Sharing Your Experiences

"It took me 3 years to set up a local survivors' group in my native community. My support group started with two people in my home and grew to ten. I think it is important to support people so that they can heal and recover."

Lahoma, bone cancer survivor, 55

If you are reading this book, you probably know a lot about cancer. Your experience can help others who are struggling. Here are some ways you can help:

- Offer to be a "buddy" to someone who is dealing with cancer. You can do this in person, by telephone, or even over the Internet.
- Tell others with your same diagnosis about the treatment choices you made and why you made the decisions you did.
- Help people get ready for their doctors' appointments by making lists of concerns they want to talk about.
- Talk to others about how you told your boss and coworkers that you have cancer.
- Ask how you can be helpful to the family and friends of someone who has cancer. Let them know that you care and are ready to listen, help, and share ideas.
- Think about volunteering to be a "peer counselor" (someone who is trained to help others with the same type of experience or diagnosis). Some cancer organizations recommend, or even require, that people be out of treatment for at least a year before they volunteer as peer counselors.
- Get involved with, offer to co-lead, or start a cancer support group in your local area.

Sharing What You Learn About Cancer

"There's a new study published every day. I want to keep up with the information my wife needs."

Harold, husband of a 63-year-old breast cancer survivor

When you learn about cancer, you not only help yourself, but you can also help others by sharing what you know. For example, you can learn about your rights as a person with cancer and teach this to others. Here are some ways to get started:

By phone

Many national cancer organizations have toll-free phone numbers you can call. They can answer your questions or send you books with more information. Sometimes cancer organizations even offer educational programs conducted over the telephone. See pages 71-97 for groups to call.

In print

There is a lot of written information about cancer. This includes magazines, newspapers, booklets, and books. Some of these print materials are written for the general public, while others are more for health professionals and scientists. Visit your local library or hospital resource center, or ask your doctor or nurse about up-to-date materials that are written at a level you can understand.

Over the Internet

Many people search for cancer information on the Internet. For example, many organizations have Web sites you can go to for the latest information about cancer. You might want to subscribe to an organization's e-mail list and get messages when the site is updated. Some Web sites also offer listservs or chat rooms where people can meet each other on line. These are ways that people interested in cancer can exchange messages about their experiences, concerns, and resources. See pages 71-97 for Internet sites. (To learn more about the Internet, see page 65 for "Using the Internet for Medical Advice.")

Going to meetings, workshops, or classes

Many people help themselves as well as others by going to meetings, workshops, and classes. They can learn about clinical trials, a new approach to relaxation, or how to deal with other problems long after treatment is over. Ask your local hospital or cancer center about cancer-related programs they offer the general public. Often, you can attend these programs for free or at a low cost.

Working With Others in Your Own "Backyard"

You don't have to travel a long distance to help others. In fact, there are many ways you can make a difference in your own "backyard"—where you live, work, go to school, or worship. You can talk with people about cancer and keep them up to date with the latest facts and information. Tell them about your experience with cancer and help them learn more.

For example, you can:

- Bring cancer brochures to your workplace, school, or place of worship. You may be able to get brochures from cancer organizations such as the ones listed in the back of this book.
- Tell people about a cancer screening day, or help organize one.
- Organize a team for a cancer fundraising event, such as a walk or run in your community.
- Start a support group for people affected by cancer. There may be some people where you work or go to school who want to talk about their ideas, feelings, and experiences with cancer.
- Ask your employer, school, or place of worship to make a donation, sponsor a cancer-related event, or offer cancer screening tests.
- Write an article about cancer for your school or workplace newsletter or a local newspaper.
- Find ways to help make your workplace easier for people with cancer or other health problems.
- Help people understand their legal rights as cancer survivors (see page 94).

Ways Others Have Helped in Their Own "Backyards"

- Members of a cancer support group were trained to help at a local hospice. They gave comfort to patients during their last days and showed kindness to their friends and family members.
- Older, trusted members of one community reached out to their neighbors about cancer screening. Known as "lay health advisors," they encouraged other older adults to get screened for cancer.
- A hospital organized a "Patient Navigator Program" in which survivors helped people who had cancer but did not have health insurance. They worked together throughout the person's cancer treatment.
- Some groups have found ways to help others who share their faith, background, or culture. A group of African-American women with cancer organized a support group to deal with their unique needs. And a local church started a program to spread the message about the importance of early breast cancer detection.

?

What if people ask me questions that I can't answer?

People will ask you questions about cancer, and sometimes you won't know the answer. It's okay to say, "I don't know," but let the person know that you will try to learn the answer. One way you can learn more is by contacting a cancer organization by phone, e-mail, or letter. (See pages 72-93 for a list of cancer organizations.)

Talking With Doctors, Nurses, and Other Health Care Providers

If you are a cancer survivor or are close to someone who has or has had cancer, you know what it is like to talk with doctors, nurses, and other health care providers. You may have learned how to speak up and ask questions—and you can use your experience to help others. For example, you can:

- Let people know that they should talk with their doctor about *all* their concerns—even the little ones that do not seem important.
- Help patients and their families get ready for medical appointments. You can suggest that they:
  - Write a list of their questions and bring it with them when they see the doctor.
  - Bring a paper and pen to take notes about what the doctor says.

- Suggest that patients and their families invite someone to go with them to their appointments. This can be a family member, friend, or volunteer.
- Make sure that all health care providers treat everyone with respect. This includes respecting not only people with cancer, but also their families and loved ones. (See "The Cancer Survivors' Bill of Rights" on page 67 for more information.)

- Volunteer at hospice programs, helping people through their last days.
- Join a Patient and Family Advisory Board. Hospitals and cancer centers often want survivors and their families to help them develop new programs. When you are on a Patient and Family Advisory Board, you may be asked to give advice on policies and programs and let the organization know how it can improve care for all patients.

Keep in Mind

If you offer to go to a doctor's appointment with someone, make sure you agree on what he or she would like you to do. Ask the patient ahead of time if you should:

- Stay in the waiting area or go into the exam room.
- Ask questions or help explain any words or terms the patient doesn't understand.
- Bring paper and pen or a tape recorder to take notes. You can offer to take notes about when to come back for an appointment or how to take a new medication.

Ways to Get Started— Helping Others in Everyday Ways

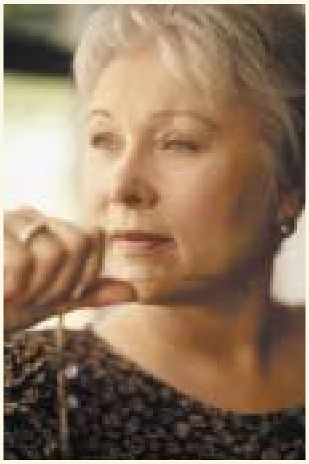
Once you decide that you want to make a difference in everyday ways, find out who needs your help and what you can do to get started. Here are some ideas about ways to begin:

- **Let people know that you want to help others.** Tell your family, neighbors, coworkers, and even your doctor that you want to get involved in cancer-related activities. Talk with them about things you like to do and ways you want to help. Ask for their ideas and suggestions. Make sure to let them know when and how you have decided to help.
- **Find out about volunteer programs where you live.** Check with your local hospital or cancer center, clubs, senior centers, and places of worship to see if they have programs to help people with cancer. If any of these groups have volunteer programs, ask how you can get involved. If there isn't a program nearby, think about starting one.

After you have worked with others in everyday ways for a while, think about how you liked this experience. One way is to fill out the Guide on page 63, **"Thinking About Your Choices: A Guide."**

- **Look in your local newspaper for volunteer opportunities.** Many newspapers, libraries, and community centers have lists of organizations that need volunteers. You can also find the names and addresses of cancer-related organizations at the back of this book. (See pages 72-93 for more information.)
- **Get involved with a cancer organization.** Contact a cancer-related group that interests you. Talk with the person in charge of volunteers about your interests and experiences. He or she might suggest that you get involved with a cancer support group, telephone hotline, or patient education program. (For more information, go to the tab: *Cancer-Related Organizations*.)

Making a Difference With Cancer-Related Organizations



After 8 years, I am still volunteering … I have made some wonderful friends—they often know what I am feeling before I even say it because they've been where I am. We helped raise money for cancer research that, I hope, someday will lead to a cure.

"My oldest sister, Elizabeth, was diagnosed with lung cancer 10 years ago. From the moment she found out she had cancer, she knew it was bad. She had chemo, radiation, and part of her lung removed—and still her cancer came back. She died when she was 59 years old, three days after her grandson's first birthday.

During Elizabeth's illness, I felt angry, sad, powerless, and frustrated. I went around like this until someone showed me an ad for a local organization that was raising money for cancer research. I thought, 'Here is another group asking for money I don't have.' But I read more, and the ad said they were looking for volunteers to help out at their office. I'm not sure why I decided to call them or what made me go down there, but I did.

Someone asked me to start stuffing envelopes, and that's how I got started. That first night there were about 20 of us helping to get ready for an event. Some people were making posters. One man was on the phone taking pledges. Another lady was trying to get the caterer to lower its prices.

I was hooked right away. I knew this was a way to channel all my feelings of anger, helplessness, and hopelessness into something good. I was with other volunteers who also were cancer survivors and knew what I had been through.

After 8 years, I am still volunteering with that group. Why do I do it? I have made some wonderful friends—they often know what I am feeling before I even say it because they've been where I am. We helped raise money for cancer research that, I hope, someday will lead to a cure.

While it will not help my sister, I do this work to honor her memory."

Carol, lost a sister to lung cancer, 57

About Making a Difference with Cancer-Related Organizations

The last chapter described how you can make a difference in everyday ways. This chapter looks at how you can help by working with cancer-related organizations. Cancer-related organizations include many different kinds of groups that find ways to help people with cancer—and many of them need the help of volunteers. Many of these groups are listed in the back of this book, starting on page 72.

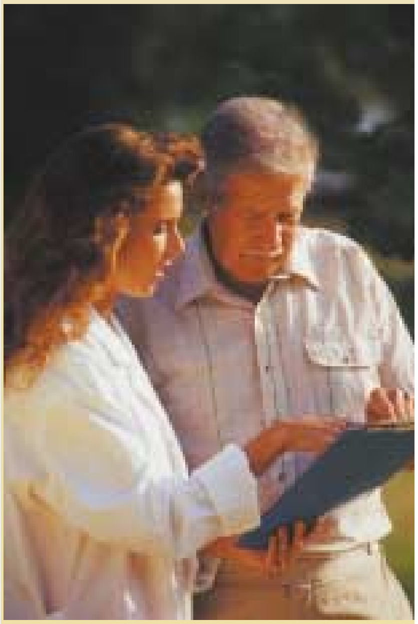
Some cancer-related organizations serve only their local communities, while others help people in certain regions of the country. National organizations serve people all across the United States.

Cancer organizations can focus on different areas:

- All types of cancer
- Just one type of cancer
- The needs of people from a specific racial or ethnic group, religion, or culture
- The needs of family members or other people who take care of those with cancer

Cancer-related organizations offer many different kinds of services:

- Service and support
- Awareness and education
- Fundraising
- Advocacy



Keep in Mind

Think about your interests, and decide if you want to volunteer with a cancer-related organization that helps people who:

- Have one type of cancer
- Have different types of cancer
- Share your background
- Live in your area
- Live across the United States

Working With Service and Support Organizations

"When I was in treatment, I had trouble finding people like me to talk to. I finally found a local group that was working to help other Hispanic women and lesbians deal with and understand cancer—to give them someone to talk to. So that's where I started volunteering."

Consuelo, ovarian cancer survivor, 51

Service and support organizations make sure people don't have to face cancer alone. They offer help to survivors, caregivers, and people who lost someone to cancer. These groups provide services such as:

- **Telephone hotlines.** In these programs, volunteers are trained to be hotline counselors: people who give easy-to-understand information over the phone. Hotline counselors also are trained to be good listeners and support other people as they talk about their feelings and concerns. Some hotlines let volunteers take calls in their homes.
- **Cancer support programs.** These programs give emotional support to people with cancer and their families. They also help by giving people items they need, such as wigs, scarves, breast forms, and books.
- **Other types of support.** These include help with medical services, including referrals for second opinions or specialists. They also include legal services as well as practical help people need, like rides to medical appointments.

Ways to Get Started— Service and Support Programs

- Donate items cancer patients need, like wigs, scarves, and breast forms.
- Provide office help such as answering phones or stuffing envelopes.
- Volunteer to drive people to their doctors' appointments.
- Join a support group, or offer to lead one.
- Get trained to work as a hotline counselor.
- Join a committee that helps plan programs, or let others know about services.

Working With Awareness and Education Organizations

Cancer organizations also work hard to raise awareness about cancer. They do this by letting people know that cancer can affect anyone and giving people facts and figures about the disease. Cancer organizations also invite people to join them in the fight against cancer.

Organizations also educate people about cancer. This includes teaching people about cancer screening tests, ways to reduce cancer risks, and tips for healthy living. Organizations want to get this message out to as many people as they can. They often give workshops and presentations at schools, workplaces, places of worship, health fairs, and even over the Internet.

Ways to Get Started—Awareness and Education Programs

- Provide needed help around the office.
- Help at local health fairs and community events.
- Give your family, friends, and coworkers information about cancer. Ask them to help you teach others about this disease.
- Think of new ways to let people know about cancer. Find booklets and brochures about cancer you think people will read.
- Organize a cancer screening in your community.
- Learn how to teach a session about cancer at your workplace or in your community group.
- Join a committee that plans new programs or lets others know about your work.

Working With Fundraising Organizations

Cancer organizations all need to raise funds (get money) in order to provide the services people need and want. Many groups also raise money for cancer research.

Fundraising is often done through events such as races or shows. These events not only bring in money, but also raise awareness about cancer and give hope to the people who participate.

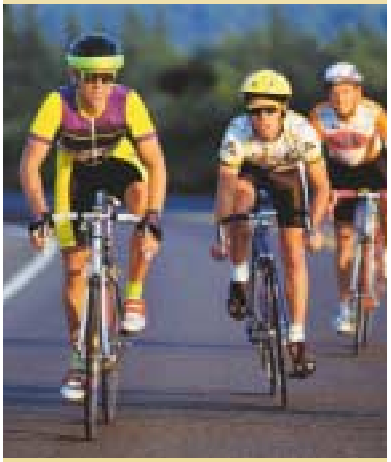
Types of Fundraising Events

There are many kinds of fundraising events. They may raise money for cancer screening, outreach, education, or research. Here are some examples:

- Walks, runs, and races. Many of these events take place on weekends; some take 2 or 3 days to complete.
- Activities like golf, bowling, cycling, and dancing.
- Luncheons, dinners, and fashion shows.
- Plays and concerts.

Ways to Get Started— Helping With Fundraising Events

- Look for events in the newspaper or through a local group (many of the national organizations on pages 72-93 have local groups or chapters).
- Take part in the event, and encourage others to do the same.
- Buy a ticket or make a donation to the event.
- Donate food or items for raffles or auctions.
- Sponsor someone to take part in a race or game.



- Help before the event by:
    - Stuffing envelopes or hanging signs.
    - Doing the artwork for an invitation.
    - Asking your local newspaper or radio station to announce the event.
    - Putting up posters, handing out fliers, or sending e-mail messages to people who may want to attend. Ask people to forward this information to their family and friends.
- Help on the day of the event by setting up, cleaning, or decorating.
- Help after the event by thinking of new ways to raise money and finding volunteers to work on these events.
- Organize a fundraising event in your community.

Keep in Mind

What you should know about fundraising events:

- Every organization that raises money needs to publish its budget and annual report. The organization has to state where the funds go and how much is given to cancer-related activities.
- Find out ahead of time how the organization plans to use the money you raise. You might want to ask:
    - How will the money be spent?
    - Who decides how the money will be spent?
    - What percent of the money goes to program costs and office expenses?
    - Does the event support all types of cancer or just one type?
    - Does the money stay in the community or go to a national organization?

Working With Advocacy Organizations

"We've educated elected officials about our struggles with cancer … and I've gotten my support group to gather lots of signatures on our latest petition drive. It makes me feel that I am making a difference for others who are going to face this disease."

Kelly, Hodgkin's disease survivor, 42

Advocacy (or *advocate*) means to support, speak in favor of, or recommend a specific cause. For example, cancer organizations advocate by:

- Helping people with cancer get the care they need, even if they do not have health insurance or cannot pay for it.
- Protecting people from discrimination (being treated unfairly) because they have cancer or other health-related problems.
- Raising awareness about cancer, and teaching people about the need for more services, education, and research.

Ways to Get Started—Advocacy

- **Become an active, involved citizen, and consumer.** For example, you can lead a city, state, or regional effort to get more people involved in cancer policy issues. You can also speak about these issues at meetings, health fairs, and other public events.
- **Get to know your elected officials** and talk with them about your cancer concerns.
- **Sign a petition on cancer issues.** Advocacy groups often use petitions as a way to bring attention to cancer issues.

- **Join an advocacy committee** and see what kind of help they need. They may ask you to make phone calls, write letters, or organize an event. If there is not a group near you, think about starting one, or see if you can help by phone or e-mail.
- **Sign up to receive cancer "alert" announcements.** Many advocacy groups mail, fax, or e-mail alerts about important cancer issues. Keep up to date, and ask your friends and neighbors if they want to get this information as well.

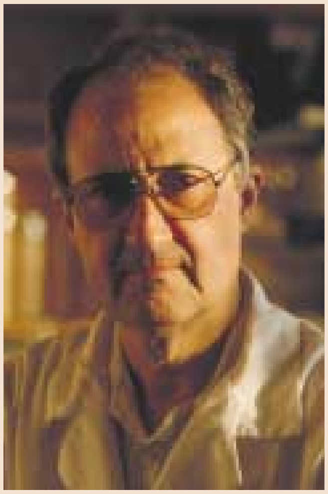
Ways to Get Started— Cancer-Related Organizations

- Learn about what types of activities interest you. The Guide on page 15 can help you think about the kinds of activities you like to do and are good at.
- Find cancer-related organizations by going to the list starting on page 72. Many of these groups have local chapters. You can also find local groups by calling your local hospital, searching the Internet, or asking a friend, neighbor, or someone at your doctor's office.
- Contact organizations that interest you and ask for information about their programs. Start by going to one of their events or talking with someone who organizes volunteers. See if there is a "good fit" between your interests and what they do.

After you have worked with a cancer-related organization for a while, think about how you liked this experience. One way is to fill out the Guide on page 63, **"Thinking About Your Choices: A Guide."**

Making a Difference

In Cancer Research



I tell everyone that if you want to take an active role in deciding your treatment, learn about clinical trials and decide if they're right for you.

"I found out I had cancer 6 years ago, just after my 45th birthday. I started learning as much as I could about my cancer. I wanted to know about all my treatment options. I am lucky because my wife's best friend is a nurse. She told me that for many cancers, some of the best treatments are clinical trials. I remember I said, 'Are you crazy? I'm not going to be anybody's guinea pig.' Then she told me, 'Don't close your mind to this before you know all the facts. Sometimes clinical trials can offer the best treatments available.'

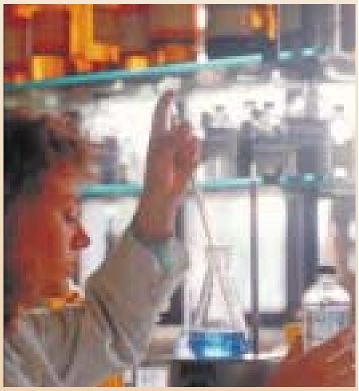
So I found out everything I could about clinical trials. My doctor and I talked about this together, and she referred me to a trial. After a lot of thought and talking it over with my family, I decided to sign up. That's how I got my cancer treatment.

I've been out of treatment for about 4 years now, and so far, things look good. I am not saying that clinical trials are right for everyone. I'm not even saying I'm cured. I'm just saying I got informed and learned about all my options.

I tell everyone that if you want to take an active role in deciding your treatment, learn about clinical trials and decide if they're right for you. I help people understand that they're not 'guinea pigs' when they take part in a trial.

Clinical trials helped me. But more than that, I feel like I am helping others who may someday get cancer. Maybe my decision to take part in a clinical trial will help improve treatment for others. Maybe my story will help others find the treatment they need. I know that my cancer experience is not in vain."

Chris, colon cancer survivor, 51



About Making a Difference in Cancer Research

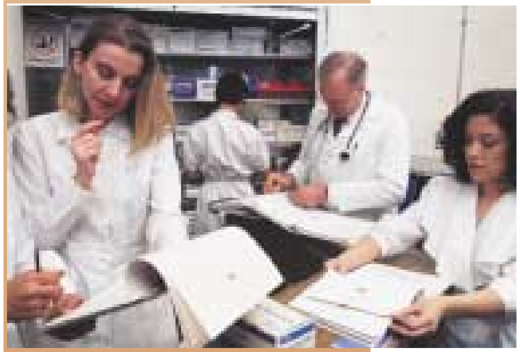
Research is the key to improving treatments for cancer. The more people take part in clinical trials, the faster we can answer important research questions, leading to better treatment and prevention options for all cancers.

Cancer research takes place at hospitals, universities, government facilities, and private companies. There are many ways you can get involved with research: taking part, encouraging others to do so, and helping to influence how research is done.

Taking Part in Cancer Research

Clinical trials are research studies in which people help doctors find ways to improve cancer care. Each study tries to answer scientific questions and find better ways to prevent, diagnose, or treat cancer.

Cancer treatment clinical trials test whether a new drug or procedure is effective, but there are many other kinds of clinical trials and types of research studies you can take part in. For example, there are:



- Clinical trials that focus on cancer prevention, cancer screening, and quality of life.
- Research studies that ask survivors and their families to fill out surveys or take part in interviews. These studies focus on understanding more about:
    - The things people do or are exposed to that may affect their health.
    - How cancer and its treatment affect their lives.
    - The medical costs of cancer and its treatment.

Taking part in a research study—after learning everything you need to know about it—is an important way you can give to others and, perhaps, help yourself at the same time. You can also make a difference by telling others about how they can participate in clinical trials.

Influencing Cancer Research

"My 13-year old son died of cancer. So, I have a unique viewpoint that I can share with other parents and scientists. I learned that research is where the answers are—like how new treatments get to the clinics for kids. I have also become an advocate and use my skills to help doctors and scientists understand what parents of children with cancer go through."

Juana, lost her son to cancer, 53

Doctors and scientists take a lot of time to design a study before the research can start. They need to decide what topics to research, how the research will be done, and how it will be funded.

It's not just doctors and scientists in lab coats who need to think about these issues.

People who have had cancer and others who are concerned about cancer (often called consumer or patient advocates) are beginning to have a voice in how research is funded. Consumers bring an important point of view to the research process. They explain what is really important to people who have cancer. They also help scientists think about what it is like for patients to take part in cancer research.

Whether sponsored by a private organization, a state government, or the Federal Government, cancer research programs must review applications to decide which projects to fund. For example:

- Many foundations raise money for cancer research, education, and outreach programs and then award funds to projects they feel are worthy.
- Many states, as well as the Federal Government, run programs in which they award funds to scientists for cancer research.

Many of these programs invite consumers to join committees that help decide which research gets funded. Consumers can bring a community perspective to these important decisions. By serving on these committees, consumer reviewers help advocate for:

- Innovative research studies that will benefit patients sooner and more effectively
- Improved medical care
- Improved quality of life for patients, survivors, and their families

There are many different programs that seek consumer input into what research gets funded. (See the list on pages 51-52; many organizations on pages 71-93 also have funding programs).

Joining an Institutional Review Board

Another way you have an influence in research is by joining an institutional review board (IRB) at your local hospital, cancer center, or university. An IRB is made up of doctors, nurses, and people from the community. Its job is to review research studies and make sure they are run in a manner that is safe and fair. IRB members also look at informed consent documents and make sure they are easy to understand and have all the information people in the study need to know.

Ways to Get Started—Cancer Research

If you are interested in cancer research, here are some ways you can get started.

To learn more about clinical trials:

- Contact the National Cancer Institute (NCI) to find out more about clinical trials. For example, you can:
    - Learn more about how clinical trials have helped find better treatments for people with cancer.
    - Find out how you can teach others about participating in these studies.
    - Find out where clinical trials are taking place in your area.

  You can find more information about clinical trials on pages 51 and 71.
- Talk to your doctor about clinical trials in your area. Some of these studies may also be listed in your local newspaper.

To learn more about influencing cancer research:

- Contact the research office at your local hospital, university, or cancer center. Ask to speak with the researchers to learn more about their work.
- Learn about research in your community by visiting the NCI Research Portfolio Web site at:

  http://researchportfolio.cancer.gov.

  You can search this site by state, institution, or name of researcher.
- Contact your state's health department and ask about the cancer research programs it funds. Find out which studies are looking for consumers to get involved.
- To find local cancer programs, look in your telephone book under "Departments of Health" or "Health Departments."
- Find out about the private foundations in your area that fund cancer research, and ask if they would like consumer input. (To learn more, go to the list of cancer organizations starting on page 72.)
- Call or write the Federal Government programs at the numbers listed on the next page, and ask for an application to be a consumer or patient representative.

Federal Government Programs That Welcome Consumer Involvement

Government Program	Description
National Cancer Institute	
Consumer Advocates in Research and Related Activities (CARRA) NCI Liaison Activities (LA) Branch 6116 Executive Blvd., 3068A Bethesda, MD 20892-8324 Tel: 301–594–3194 http://la.cancer.gov/carra E-mail: liaison@od.nci.nih.gov	The Consumer Advocates in Research and Related Activities (CARRA) program encourages people affected by cancer to provide their viewpoints and ideas directly to NCI staff so that the NCI can incorporate their perspectives into its programs and activities. CARRA members represent many different cancer types, age groups, and ethnic groups from across the nation. In addition to participating in NCI activities, CARRA members represent the opinions of their groups and play critical roles as two-way information links between their own communities and constituencies and the NCI. CARRA members meet directly with NCI staff. They may: • Review proposals during scientific peer review. • Participate in meetings about NCI research plans and policies. • Develop and review health promotion messages.
Clinical Trial Cooperative Group Program See the Cooperative Group Program link on the Web site by going to *http://ctep.cancer.gov*, and following the links on your screen. Or call the National Cancer Institute's Cancer Information Service at **1–800–4–CANCER** to request a fact sheet that lists cooperative groups.	Clinical trials are often conducted through NCI Clinical Trial Cooperative Groups, which are networks of institutions that jointly carry out large clinical trials. Members of these groups include: • University hospitals • Cancer centers • Community doctors and community hospitals There are ten cooperative groups; some focus on type of cancer, others on type of treatment, and at least one on age of participants. Other groups are regional or focus on several cancer types. Cooperative groups seek the input of patients in their committees and working groups. Some patient advocates may be involved in developing research plans (called protocols); others may help develop informed consent forms; and others are involved in advising on policies or priorities. The application process is different for each cooperative group.

Government Program	Description
U.S. Department of Defense	
Congressionally Directed Medical Research Programs (CDMRP) Congressionally Directed Medical Research Programs ATTN: Consumer Recruitment 1077 Patchel Street Fort Detrick, MD 21702-5024 Tel: 301–619–7079 http://cdmrp.army.mil E-mail: cdmrp.consumers@det.amedd.army.mil	Currently, the CDMRP oversees research programs in Breast Cancer, Prostate Cancer, Ovarian Cancer, and Chronic Myelogenous Leukemia. In these programs, Consumer Reviewers take part in reviewing research proposals along with scientists (called "peer review"). Consumer Reviewers: • Represent the collective views of survivors, patients, family members, and persons affected by and at risk for a disease. • Read and evaluate research study proposals for relevance to the consumer community's needs and concerns. • Actively participate in the discussions and decision-making process of peer-review panels. • Participate equally with scientists as full voting members.

After you have worked in cancer research for a while, think about how you liked this experience. One way is to fill out the Guide on page 63, "**Thinking About Your Choices: A Guide.**"

Making a Difference

In Government Programs and Policies

The way I see it, we have to play a role in our government. You can't just sit in front of your TV and complain. If you don't make a change, then who is going to do it?

"I found out I had prostate cancer over 10 years ago. During treatment, I got involved in a local support group for prostate cancer survivors. The more I talked with the other men in my group, the more I saw how little most of us knew about the disease. I made it my mission to help men learn as much as they could about prostate cancer.

I started out talking about getting screened for cancer to the men I knew—my family, friends at church, and my neighbors. Then I started going to prostate cancer meetings so I could get information to take back to my community.

Later on, someone nominated me to be on a government committee about funding for prostate cancer research. Since then, I have been on lots of government committees to help make decisions about cancer research. When I'm working with these groups, I speak for the men back home and all the other men who also face prostate cancer.

The way I see it, we have to play a role in our government. You can't just sit in front of your TV and complain. If you don't make a change, then who is going to do it? The bottom line is that you have to get out there and make a difference."

Jim, prostate cancer survivor, 65

About Making a Difference in Government Programs and Policies

Survivors and their families can make a difference in the types of programs the government offers to people with cancer (or people at risk for developing cancer). They can bring an important community perspective to government programs.

Government programs often seek advice about how best to develop cancer screening programs, approve new medicines, or develop new research priorities.

Working With Local and State Government Cancer Programs

Many local, county, and city health departments have cancer education, awareness, and screening programs. To ensure that programs work well, these departments often ask survivors and their family members to get involved. For example, a local health department might ask for advice about a cancer screening program or a new brochure.

States also offer programs to reduce cancer deaths and improve cancer care. These programs may focus on cancer education, prevention, early detection, or treatment. For example, a state may run a program educating older men about prostate cancer. These state programs may need help finding the names of local organizations to work with them.

Working With National Government Cancer Programs

Just as local governments need the advice of consumers, the Federal Government has several programs that seek the advice of cancer survivors and their families. Several programs are described below.

Government Program	Description
National Cancer Institute (NCI)	The National Cancer Institute seeks consumer input and feedback on many of its policies and programs.
Consumer Advocates in Research and Related Activities (CARRA)	The CARRA program is described in more detail on page 51.
Director's Consumer Liaison Group (DCLG) Liaison Activities Branch 6116 Executive Blvd., 3068A Bethesda, MD 20892-8324 Tel: 301–594–3194 http://la.cancer.gov e-mail: liaison@od.nci.nih.gov	The DCLG is the all-consumer advisory group for the NCI. Consumers look at a range of issues, programs, and research projects and make recommendations based on their consumer perspective. There are 15 consumer advocates on the DCLG, each serving a 3-year term. They are chosen to reflect the diversity of those whose lives are affected by cancer. To learn more about the DCLG (including a membership roster and meeting summaries), go to the NCI Web site at www.cancer.gov, click on "About NCI," and then select "Advisory Boards and Groups."

Government Program	Description
Food and Drug Administration (FDA)	Several FDA programs have patients and consumers on their scientific and technical advisory committees. Training is provided to people who are selected.
Cancer Drug Development Patient Consultant Program Office of Special Health Issues (HF-12) Food and Drug Administration 5600 Fishers Lane Rockville, MD 20857 Tel: 301–827–4460 http://www.fda.gov/oashi e-mail: oshi@oc.fda.gov	This program provides cancer patient advocates an opportunity to participate in the FDA drug review regulatory process. Patient advocates serve as patient consultants in the preapproval, clinical trial phase of cancer drug development. Patient consultants provide advice to the FDA and drug sponsors on topics such as clinical trial design, endpoint determination, expanded access, protocol development, and clinical trial patient recruitment strategies.
Cancer Patient Representative Program (Address same as above)	This program provides the FDA and its advisory committees the unique perspective of patients and family members directly affected by a serious or life-threatening disease. Patient Representatives serve on advisory committees when a product or therapy (drug, biologic, or medical device) related to a serious or life-threatening disease is under review. Patient Representatives must be well informed about patient concerns and have the ability to understand and actively participate in advisory committee discussions.

Government Program	Description
Food and Drug Administration (FDA)	
Consumer Representative Advisory Committees Food and Drug Administration Advisory Committee Oversight and Management Staff (HF-4) 5600 Fishers Lane, Room 16-85 Rockville, Maryland 20857 Tel: 301–827–1220	These committees seek input from consumers on medical and scientific issues. Consumer representatives must be able to analyze data, understand research design, discuss benefits and risks, and evaluate the safety and effectiveness of products under review.

Ways to Get Started—Government Programs

Decide if you want to get involved at the local, state, or national level. You may want to start out in your home county or state.

If you think you may be interested in local cancer programs, a good way to start is by speaking with the person in charge of cancer-related programs at your local health department. Ask for information about the programs they offer and find out how you can help.

- To find local cancer programs, look in your telephone book under “Departments of Health” or “Health Departments.”

If you think you may be interested in state cancer programs, you can speak to someone who works on cancer in your state health department. Ask for information about their programs and find out how you can help.

- To find cancer programs run by state governments, contact:
  U.S. Centers for Disease Control and
  Prevention (CDC)
  Tel: 1-888-842-6355
  http://www.cdc.gov/cancer/ncccp/contact.htm

If you think you may be interested in national programs:

- Learn more about the programs listed in this section by calling, writing a letter, or looking at their Web sites.
- Request applications for the programs that interest you. Even if you find they are not right for you, you can share them with others.

After you have worked in government programs and policies for a while, think about how you liked this experience. One way is to fill out the Guide on page 63, **"Thinking About Your Choices: A Guide."**

Making a Difference

Resources to Learn More

Thinking About Your Choices:

A Guide

After you've done some work in cancer-related activities, think about the choices you made. Then, answer the questions below.

1. What did you do to make a difference in cancer?

EXAMPLE:

I called my local cancer center volunteer office; found out about a training to help other survivors; went to the training and was a buddy to two men diagnosed with prostate cancer.

____

____

____

2. Did you find this was the right time for you to get involved?

☐ Yes ☐ No

If **NO**, think about waiting a little while and trying again.
If **YES**, answer the next questions:

3. What did I like best?

____

____

____

4. What did I like least?

____

____

____

5. Do I like doing this work?

☐ Yes ☐ No

It may take some time to find the activity you like best. Sooner or later, you will find an activity that is the right match for you.

If **NO**…

If you don’t like this activity or organization, think about changing what you are doing. For example:

- If you are working on your own, think about working with an organization.
- If you are working with an organization, think about working on your own.
- Switch to another area of interest.
- Switch to another organization.

If **YES**…

If you like what you are doing, you can:

- Keep doing it.
- Decide whether you want to do more. Read this book again and find other activities that interest you.

Remember to slow down. You need to take care of yourself before you can make a difference in the lives of others.

Using the Internet for Medical Advice

The Internet is a tool many people use to find medical information and advice. This includes Web sites as well as online discussion groups such as listservs and chat rooms.

The Internet can be a valuable source of information about cancer. But sometimes Internet information can be false, unreliable, or misleading. Don't believe everything you see on the Internet. Talk with your doctor about the medical advice you find and make sure the information makes sense for you.

Here are eight questions to keep in mind when using the Internet for medical advice.

1. Who runs this site?

All Web sites should include the name of the organization that sponsors (pays for) it, as well as the person who runs the Web site.

2. What is the purpose of the site?

The purpose (or goal) of the site should be clearly stated. You can often find this by clicking on a link that says, "About This Site," or similar words.

3. Who pays for the site?

It costs money to run a Web site. Find out if the site includes advertisements such as "banner ads." Think about the company that pays for the site; they may only want you to know about their services or products.

4. Where does the information come from?

Many Web sites include information from other sources. The Web site should make clear where information comes from. All medical articles should have a list of references where you can go to learn more. Opinions and advice should be clearly labeled and set apart from information based on research results.

5. How is the information selected?

Is there an editorial board? Do people with good medical qualifications review the material before it is posted?

6. How current is the information?

Web sites should be reviewed and updated on a regular basis. It is important that medical information be current and that its most recent update or review date appears on the site. Even if the information has not changed, you need to know that the site "owners" have reviewed it recently to make sure the information is still correct.

7. How can users contact the Web site "owners"?

There should always be a way for you to contact the site owners with problems, feedback, and questions.

8. How does the chat room or discussion area work?

If the site has a chat room or other online discussion areas, it should tell you how the service works. Is it led by someone? By whom, and why? It is always a good idea to spend time reading the discussion before joining in, so that you feel comfortable with the environment before you get involved.

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What if I do not have access to the Internet at home?

Your local library, school, or university may have computers that the general public can use to access the Internet. Call ahead and ask if they can help you get on line. You can still get cancer information even if you do not have access to the Internet. Call 1-800-4-CANCER (1-800-422-6237) and ask them to mail you cancer information. You can also ask your doctor, library, or a family member or friend to help you find cancer information.

The Cancer Survivors' Bill of Rights

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

The National Coalition for Cancer Survivorship presents this 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.

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 followup 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.

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.

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.

In the workplace, 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 to not 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.

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.

Getting Information from the National Cancer Institute

Cancer Information Service

The Cancer Information Service (CIS), a program of the National Cancer Institute (NCI), is a resource for information and education about cancer. Through the CIS toll-free telephone number, callers can speak with knowledgeable staff who can explain medical information in terms they can easily understand. CIS staff can provide:

- Answers to questions about cancer.
- Written materials from the NCI.
- Referrals to clinical trials and cancer-related services.
- Assistance in quitting smoking (from information specialists trained in smoking cessation counseling).

To speak with a CIS information specialist or to order publications on the phone:

Call 1–800–4–CANCER (1–800–422–6237), 9:00 a.m. to 4:30 p.m., local time, Monday through Friday. Deaf or hearing-impaired callers with TTY equipment should call 1–800–332–8615.

For information 24 hours a day, 7 days a week:

Call 1–800–4–CANCER and select Option 4 to hear recorded information.

To obtain online assistance with cancer information:

Visit the CIS Web site at http://cis.nci.nih.gov and click on the LiveHelp link between 9:00 a.m. and 5:00 p.m., Eastern time, Monday through Friday.

To order publications online:

NCI provides access to a large number of publications. To order these materials, go to the NCI home page, www.cancer.gov, and click on "Publications Locator." Follow the instructions on your screen.

Organizations Where You Can "Make a Difference"

The following organizations provide information, support and other resources to cancer survivors and those who have helped someone through cancer. Many of these groups may also have volunteer opportunities in your community, or at the state or national level.

NOTE: This list was current as of spring 2002. For an up-to-date list of groups, see the NCI Fact Sheet: "National Organizations That Offer Services to People With Cancer and Their Families" (http://cis.nci.nih.gov/fact/8_1.htm), or call 1–800–4–CANCER.

Cancer Organizations

General Organizations

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	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."
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. It offers a toll-free nutrition hotline, pen pal support network, funding of research grants, and a wide array of consumer and health professional brochures and 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.

General Organizations (continued)

Contact Information	Description
Cancer Care, Inc., National Office 275 Seventh Avenue New York, NY 10001 Tel: 1–800–813–HOPE (1–800–813–4673) 212–221–3300 (Administration) 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. 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.
Cancer Hope Network Two North Road, Suite A 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 http://www.amc.org/html/info/h_info_cicl.html 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 patients, their family members and friends, cancer survivors, and the general public. Professional counselors provide up-to-date medical information, emotional support through short-term counseling, and resource referrals to callers nationwide between the hours of 8:30 a.m. and 5:00 p.m., Mountain time. Individuals may also submit questions about cancer and request resources via e-mail.

General Organizations (continued)

Contact Information	Description
Cancer Research Foundation of America 1600 Duke Street, Suite 110 Alexandria, VA 22314 Tel: 1–800–227–CRFA (1–800–227–2732) http://www.preventcancer.org	The Cancer Research Foundation of America seeks to prevent cancer by funding research and providing educational materials on early detection and nutrition.
Gilda's Club® Worldwide 322 Eighth Avenue, Suite 1402 New York, NY 10001 Tel: 212–305-1200 http://www.gildasclub.org e-mail: info@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.
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	PAF provides education, legal counseling, and referrals for 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: 816–WE–BUILD (816–932–8453) 1–800–433–0464 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. It also distributes informational materials, including a multidisciplinary list of institutions that offer second opinions. Information is available in Spanish.

General Organizations (continued)

Contact Information	Description
Vital Options® and ***The Group Room*® Cancer Radio Talk Show** PO Box 19233 Encino, CA 91416–9233 Tel: 1–800–GRP–ROOM (1–800–477–7666) 818–508–5657 (local) http://www.vitaloptions.org e-mail: geninfo@vitaloptions.org	The mission of Vital Options® is to use communications technology to reach people dealing with cancer. This organization holds a weekly syndicated call-in cancer radio talk show called *The Group Room*®, which provides a forum for patients, long-term survivors, family members, physicians, and therapists to discuss cancer issues. Listeners can participate in the show during its broadcast every Sunday from 4:00 p.m. to 6:00 p.m., Eastern time, by calling either of the telephone numbers. A live Web simulcast of *The Group Room*® can be heard by logging on to the Vital Options® Web site.
The Wellness Community 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. It offers support groups facilitated by licensed therapists, stress reduction and cancer education workshops, nutrition guidance, exercise sessions, and social events.

Bone Marrow Donors/Recipients

National Bone Marrow Transplant Link (nbmtLink) 20411 West 12 Mile Road, Suite 108 Southfield, MI 48076 Tel: 1–800–546–5268 http://comnet.org/nbmtlink	The nbmtLink motto is “A Second Chance at Life is Our Priority.” The nbmtLink operates a 24-hour, toll-free number and provides peer support to bone marrow transplant (BMT) patients and their families. It serves as an information center for prospective BMT patients as well as a resource for health professionals. Educational publications, brochures, and videos are available. Staff can respond to calls in Spanish.

Bone Marrow Donors/Recipients (continued)

Contact Information	Description
National Marrow Donor Program® (NMDP) 3433 Broadway Street, NE, Suite 500 Minneapolis, MN 55413 Tel: 1–800–MARROW–2 (1–800–627–7692) 1–888–999–6743 (Office of Patient Advocacy) http://www.marrow.org	NMDP, which is funded by the Federal Government, was created to improve the effectiveness of the search for bone marrow donors. It keeps a registry of potential bone marrow donors and provides free information on bone marrow transplantation, peripheral blood stem cell transplant, and unrelated donor stem cell transplant, including the use of umbilical cord blood. NMDP's Office of Patient Advocacy assists transplant patients and their physicians through the donor search-and-transplant process by providing information, referrals, support, and advocacy.

Hospice

HOSPICELINK Three Unity Square PO Box 98 Machiasport, ME 04655–0098 Tel: 1–800–331–1620 http://www.hospiceworld.org	HOSPICELINK helps patients and their families find support services in their communities. It offers information about hospice and palliative care and can refer cancer patients and their families to local hospice and palliative care programs.
National Hospice and Palliative Care Organization (NHPCO) 1700 Diagonal Road, Suite 300 Alexandria, VA 22314 Tel: 1–800–658–8898 (Helpline) http://www.nhpco.org e-mail: info@nhpco.org	The NHPCO is an association of programs that provide hospice and palliative care. It offers discussion groups, publications, information about how to find a hospice, and information about the financial aspects of hospice. Some Spanish-language publications are available, and staff are able to answer calls in Spanish.

Lymphedema

Contact Information	Description
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	NLN provides education and guidance to lymphedema patients, health care professionals, and the general public by disseminating information on the prevention and management of primary and secondary lymphedema. It provides a toll-free support hotline; a referral service to lymphedema treatment centers and health care professionals; a quarterly newsletter with information about medical and scientific developments; support groups; pen pals; educational courses for health care professionals and patients; and a computer database. Some Spanish-language materials are available.

Ostomy

United Ostomy Association, Inc. 19772 MacArthur Boulevard, Suite 200 Irvine, CA 92612–2405 Tel: 1–800–826–0826 (6:30 a.m.–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 new ostomy patients.

Survivorship

Lance Armstrong Foundation PO 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 of those diagnosed with cancer. LAF seeks to promote the optimal physical, psychological, and social recovery and care of cancer survivors and their loved ones. The Foundation focuses its activities in the following areas: survivor services and support, groundbreaking survivorship programs, and medical and scientific research grants.

Survivorship (continued)

Contact Information	Description
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.canceradvocacy.org e-mail: info@canceradvocacy.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.

Organizations By Cancer Type

Bladder and Urologic Cancer

Contact Information	Description
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	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. It provides information on urologic disease and dysfunctions, including prostate cancer treatment options, bladder health, and sexual function. AFUD also offers prostate cancer support groups through its Prostate Cancer Network. Some Spanish-language publications are available.
Bladder Cancer WebCafe http://blcwebcafe.org	Bladder Cancer WebCafe is an online community for bladder cancer patients and those who care for them. It discusses treatment options, chemoprevention guidelines, survivor stories, a support group, and more.

Brain Cancer

American Brain Tumor Association (ABTA) 2720 River Road, Suite 146 Des Plaines, IL 60018 Tel: 1–800–886–ABTA (1–800–886–2282) http://www.abta.org e-mail: info@abta.org	The ABTA funds brain tumor research and provides information to help patients make educated decisions about their health care. The ABTA offers printed materials about research on and treatment of brain tumors and provides listings of physicians, treatment facilities, and support groups throughout the country. A limited selection of Spanish-language publications is available.
The Brain Tumor Society 124 Watertown Street, Suite 3-H Watertown, MA 02472 Tel: 1–800–770–TBTS (1–800–770–8287) http://www.tbts.org e-mail: info@tbts.org	The Brain Tumor Society provides information about brain tumors and related conditions for patients and their families. It offers a patient/family telephone network, educational publications, funding for research projects, and access to support groups for patients.

Brain Cancer (continued)

Contact Information	Description
Musella Foundation–*Clinical Trials and Noteworthy Treatments for Brain Tumors* 1100 Peninsula Boulevard Hewlett, NY 11557 Tel: 516–295–4740 http://www.virtualtrials.org e-mail: musella@virtualtrials.com	This Web site, maintained by the Musella Foundation, offers extensive treatment and clinical trial information for brain tumors.
National Brain Tumor Foundation (NBTF) 414 Thirteenth Street, Suite 700 Oakland, CA 94612–2603 Tel: 1–800–934–CURE (1–800–934–2873) http://www.braintumor.org e-mail: nbtf@braintumor.org	NBTF provides patients and their families with information on how to cope with brain tumors. This organization conducts national and regional conferences, publishes printed materials for patients and family members, provides access to a national network of patient support groups, and assists in answering patient inquiries. NBTF also awards grants to fund research. Staff are available to answer calls in Spanish, and some Spanish-language publications are available.

Breast Cancer

Community Breast Health Project 545 Bryant Street Palo Alto, CA 94301 Tel: 650–326–6686 http://www-med.stanford.edu/CBHP e-mail: info@cbhp.org	This Web site offers breast cancer information to patients and survivors of breast cancer. It includes advice as well as links to other sites that have breast cancer information.

Breast Cancer (continued)

Contact Information	Description
ENCORE*plus*® **YWCA of the USA Office of Women's Health Advocacy** 1015 18th Street, NW, Suite 700 Washington, DC 20036 Tel: 1–800–95E–PLUS (1–800–953–7587) http://www.ywca.org e-mail: cgould@ywca.org	ENCORE*plus*® is the YWCA's discussion and exercise program for women who have had breast cancer surgery. It is designed to help restore physical strength and emotional well-being. A local branch of the YWCA, listed in the phone book, can provide more information about ENCORE*plus*®.
Inflammatory Breast Cancer Research Foundation PO Box 90117 Anchorage, AK 99509 Tel: 1–877–786-7422 http://www.ibcresearch.org e-mail: librarian@ibcresearch.org	This Web site is primarily dedicated to the advancement of research on inflammatory breast cancer.
Living Beyond Breast Cancer (LBBC) 10 East Athens Avenue, Suite 204 Ardmore, PA 19003 Tel: 610–645–4567 Fax: 610–645–4573 http://www.lbbc.org e-mail: mail@lbbc.org	LBBC is a nonprofit educational organization committed to empowering all women affected by breast cancer to live as long as possible with the best quality of life. Programs include semiannual large-scale educational conferences, a quarterly educational newsletter, outreach to medically underserved women, a consumer-focused educational booklet, a library and resource center, the Young Survivors group, the Survivors' Helpline, and a Web site. These resources help women and families affected by breast cancer take an active role in their ongoing recovery from the disease regardless of educational background, social support, or financial resources.

Breast Cancer (continued)

Contact Information	Description
National Alliance of Breast Cancer Organizations (NABCO) 9 East 37th Street, 10th Floor New York, NY 10016 Tel: 1–888–80–NABCO (1–888–806–2226) http://www.nabco.org e-mail: NABCOinfo@aol.com	NABCO is a nonprofit organization that provides information about breast cancer and acts as an advocate for the legislative concerns of breast cancer patients and survivors. NABCO maintains a list, organized by state, of phone numbers for support groups.
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. It has 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.
National Breast Cancer Coalition 1707 L Street NW, Suite 1060 Washington, DC 20036 Tel: 1-800-622-2838 http://www.natlbcc.org	This organization focuses on three main goals in the fight against breast cancer: increasing cancer research, increasing access for all women to quality treatment and clinical trials, and increasing the influence of women living with breast cancer.
Susan G. Komen Breast Cancer Foundation 5005 LBJ Freeway, Suite 250 Dallas, TX 75244 Tel: 1–800–462–9273 http://www.komen.org e-mail: helpline@komen.org	The Komen Foundation fights to eradicate breast cancer by funding national grants, education, and screening and treatment projects in communities throughout the United States.

Breast Cancer (continued)

Contact Information	Description
The Witness Project® Arkansas Cancer Research Center Cancer Education 4301 West Markham, Slot 629 A Little Rock, AR 72205 Tel: 1–800–275–1183 Fax: 501–686–6479 http://www.acrc.uams.edu/Outreach/WitnessProject	The Witness Project® is a culturally competent, community-based cancer education program through which cancer survivors and lay health advisors increase awareness, knowledge, screening, and early detection behaviors in rural and lower-income African-American populations in an effort to reduce mortality and morbidity from breast cancer.
Y-ME National Breast Cancer Organization, Inc. 212 West Van Buren Street Chicago, IL 60607–3908 Tel: 1–800–221–2141 (English) 1–800–986–9505 (Spanish) http://y-me.org e-mail:help@y-me.org	The Y-ME National Breast Cancer Organization provides information and support to anyone who has been touched by breast cancer. Y-ME serves women with breast cancer and their families through their national hotline (available 24 hours a day), open-door groups, early detection workshops, and support programs. Numerous local chapter offices are located throughout the United States. A section of the Y-ME Web site, a toll-free hotline, and publications are available in Spanish.

Cancers of the Ovary, Uterus, Vulva, and Cervix (Gynecologic Cancers)

American College of Obstetricians and Gynecologists 409 12th Street, SW PO Box 96920 Washington, DC 20090–6920 Tel: 202–638–5577 http://www.acog.org	This Web site lists detailed information for patients on cancers of the ovary, uterus, vulva, and cervix.

Cancers of the Ovary, Uterus, Vulva, and Cervix (continued)

Contact Information	Description
EyesOnThePrize.Org http://www.eyesontheprize.org e-mail: pr@eyesontheprize.org	This site offers a Web community created to provide information, shared experience, resources, support, and company for women with gynecologic cancers.
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. It has 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.
National Cervical Cancer Coalition (NCCC) 16501 Sherman Way, Suite 110 Van Nuys, CA 91406 Tel: 1–800–685–553 http://www.nccc-online.org e-mail: acameren@nccc-online.org	NCCC focuses on giving support to women and their family members on issues related to cervical cancer disease, screening, treatment, and new research.
National Ovarian Cancer Coalition (NOCC) 500 Northeast Spanish River Boulevard, Suite 14 Boca Raton, FL 33431 Tel: 1–888–OVARIAN (1–888–682–7426) http://www.ovarian.org e-mail: NOCC@ovarian.org	NOCC raises awareness about ovarian cancer and promotes education about this disease. It has a toll-free telephone number for information, referral, support, and education about ovarian cancer. NOCC also offers support groups, a database of gynecologic oncologists searchable by state, and educational materials. A limited selection of Spanish-language publications is available.

Cancers of the Ovary, Uterus, Vulva, and Cervix (continued)

Contact Information	Description
Ovarian Cancer National Alliance (OCNA) 910 17th Street, NW, Suite 413 Washington, DC 20006 Tel: 202–331–1332 http://www.ovariancancer.org e-mail: ovarian@aol.com	OCNA works to increase public and professional understanding of ovarian cancer and to advocate for research to find more effective ways to diagnose, treat, and cure this disease. The Alliance distributes informational materials; sponsors an annual advocacy conference for survivors and families; advocates on the issues of cancer to the ovarian cancer community; and works with women's groups, seniors, and health professionals to increase awareness of ovarian cancer.

Children's Cancers

Candlelighters Childhood Cancer Foundation (CCCF) 3910 Warner Street Kensington, MD 20895 Tel: 1–800–366–CCCF (1–800–366–2223) http://www.candlelighters.org e-mail: info@candlelighters.org	The CCCF is a nonprofit organization that provides information, peer support, and advocacy through publications, an information clearinghouse, and a network of local support groups. A financial aid list is available that lists organizations to which eligible families may apply for assistance.
Children's Hospice International® 2202 Mount Vernon Avenue, Suite 3C Alexandria, VA 22301 Tel: 1–800–2–4–CHILD (1–800–242–4453) http://www.chionline.org e-mail: chiorg@aol.com	Children's Hospice International® provides a network of support for dying children and their families. It serves as a clearinghouse for research programs and support groups and offers educational materials and training programs on pain management and the care of seriously ill children.
Foundation for the Children's Oncology Group (FCOG) 440 East Huntington Drive, Suite 300 PO Box 60012 Arcadia, CA 91066–6012 Tel: 1–800–458–6223 http://www.nccf.org e-mail: nccf-info@nccf.org	The FCOG supports research conducted by a network of institutions, each of which has a team of doctors, scientists, and other specialists with the special skills required for the diagnosis, treatment, supportive care, and research on the cancers of infants, children, and young adults. Advocating for children with cancer and the centers that treat them is also a focus of the FCOG. A limited selection of Spanish-language publications is available.

Children's Cancers (continued)

Contact Information	Description
National Children's Cancer Society 1015 Locust, Suite 600 St. Louis, MO 63101 Tel: 1–800–532–6459 http://www.children-cancer.com e-mail: pfs@children-cancer.com	The Society provides direct financial assistance and emotional support to children with cancer and their families.
Outlook: Life Beyond Childhood Cancer University of Wisconsin Medical School UW Children's Hospital Department of Pediatrics K4/438 Clinical Science Center 600 Highland Avenue Madison, WI 53792–4672 Tel: 608–263–6200 http://www.outlook-life.org e-mail: jaamond@factstaff.wisc.edu	Outlook is an interactive information and support system for survivors of childhood cancer and their families.
Pediatric Brain Tumor Foundation of the United States 302 Ridgefield Court Asheville, NC 28806 Tel: 1–800–253–6530 http://www.pbtfus.org e-mail: pbtfus@pbtfus.org	The Foundation seeks to find the cause and cure of brain tumors in children by supporting medical research, increasing public awareness of the disease, and aiding in early detection and treatment of childhood brain tumors.

Children's Cancers (continued)

Contact Information	Description
STARBRIGHT Foundation 1990 South Bundy Drive, Suite 100 Los Angeles, CA 90025 Tel: 1–800–315–2580 http://www.starbright.org e-mail: ford@starbright.org	The STARBRIGHT Foundation creates projects designed to help seriously ill children and adolescents cope with the psychosocial and medical challenges they face. The Foundation produces materials such as interactive educational CD-ROMs and videos about medical conditions and procedures, provides advice on talking with a health professional, and deals with other issues related to children and adolescents who have serious medical conditions. All materials are available to children, adolescents, and their families free of charge. Staff can respond to calls in Spanish.

Colon/Rectal Cancer

Colon Cancer Alliance 175 9th Avenue New York, NY 10011 Tel: 1–877–422–2030 http://www.ccalliance.org	This is a patient-centered, colorectal cancer-specific organization that offers support, education, research, and patient advocacy services.
Colorectal Cancer Network PO Box 182 Kensington, MD 20895–0182 Tel: 301–879–1500 http://www.colorectal-cancer.net e-mail: ccnetwork@colorectal-cancer.net	The Colorectal Cancer Network is a national advocacy group that raises public awareness about colorectal cancer and provides support services to colorectal cancer patients and their families, friends, and caregivers. Services include support groups; an Internet chat room; e-mail listservs for survivors, caregivers, and advocates; hospital visitation programs; and a "One on One" service that connects newly diagnosed individuals with long-term survivors. The Network also provides literature on screening, diagnosis, treatment, and supportive care for colorectal cancer.

Kidney Cancer

Contact Information	Description
Kidney Cancer Association 1234 Sherman Avenue, Suite 203 Evanston, IL 60202–1375 Tel: 847–332–1051; 1–800–850–9132 http://www.kidneycancerassociation.org e-mail: office@kidneycancerassociation.org	The Kidney Cancer Association supports research, offers printed materials about the diagnosis and treatment of kidney cancer, sponsors support groups, and provides physician referral information.

Leukemia/Lymphoma

Large Granular Lymphocyte (LGL) Leukemia Registry H. Lee Moffitt Cancer Center and Research Institute 12902 Magnolia Drive, Suite 3157 Tampa, FL 33162 Tel: 1–800–663–3488 http://www.moffitt.usf.edu/lgl-leukemia/lgl.htm e-mail: LGLreg@moffitt.usf.edu	This registry is part of the Hematologic Malignancies Program at the H. Lee Moffitt Cancer Center and Research Institute. It collects and studies information on people with LGL leukemia. It has also established a bank of blood and tissue samples from people with the disease.
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 the LLS is to find cures for leukemia, lymphoma, Hodgkin's disease, and multiple myeloma and to improve quality of life for patients and their families. The Society supports medical research and provides health education materials, as well as the following services: patient financial aid for specified treatment expenses and transportation; family support groups; First Connection (a professionally supervised peer support program); referrals; school reentry materials; and public and professional education. The Society also provides audiotapes in English and some Spanish-language publications.

Leukemia/Lymphoma (continued)

Contact Information	Description
Lymphoma Information Network http://www.lymphomainfo.net	This site is devoted to providing detailed information for those with Hodgkin's disease and non-Hodgkin's lymphoma. The site is complemented by links to other lymphoma sites for patients and physicians.
Lymphoma Research Foundation (LRF) 111 Broadway, 19th Floor New York, NY 10006 Tel: 1–800–235–6848 http://www.lymphoma.org e-mail: LRF@lymphoma.org	LRF administers a research grant program, conducts public policy and advocacy activities, oversees finance and development, and promotes professional education. In addition, LRF funds research and provides educational information on lymphoma. It offers a helpline for general information on lymphoma, as well as referrals to other resources, oncologists, clinical trials, and support groups. A buddy program is available to match newly diagnosed patients with others who have coped with the disease. Some Spanish-language publications are also available.

Lung Cancer

Contact Information	Description
Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE) PO Box 849 Vancouver, WA 98666 Tel: 1–800–298–2436 http://www.alcase.org e-mail: info@alcase.org	ALCASE offers programs designed to help improve the quality of life for people with lung cancer and their families. Programs include education about the disease, psychosocial support, and advocacy on issues that concern lung cancer survivors.
It’s Time to Focus on Lung Cancer Tel: 1–877–646–5864 http://www.lungcancer.org	This Web site is designed to increase awareness of lung cancer and its increasing impact on women. It includes lung cancer facts, recent news, and press releases.

Mesothelioma

The Mesothelioma Web 10655 Six Pines Drive, Suite 620 The Woodlands, TX 77380 Tel: 1–877–7367–6376 http://www.mesotheliomaweb.org e-mail: info@mesotheliomaweb.org	The Mesothelioma Web (MW) is dedicated to consolidating mesothelioma information, contacts, and important links in one place. Its resource coordinators are constantly on the lookout for new information, and they are available to help find answers and solutions for individual situations.

Multiple Myeloma

International Myeloma Foundation (IMF) 12650 Riverside Drive, Suite 206 North Hollywood, CA 91607 Tel: 1–800–452–CURE (1–800–452–2873) http://www.myeloma.org e-mail: TheIMF@myeloma.org	The IMF supports education, treatment, and research for multiple myeloma. It provides a toll-free hotline, seminars, and educational materials for patients and their families. Although the IMF does not sponsor support groups, it does keep a list of other organizations’ support groups and provides information on how to start a support group. A section of the IMF Web site and some printed materials are available in Spanish.

Multiple Myeloma (continued)

Contact Information	Description
The Multiple Myeloma Research Foundation (MMRF) 11 Forest Street New Canaan, CT 06840 Tel: 203–972–1250 http://www.multiplemyeloma.org e-mail: themmrf@themmrf.org	MMRF supports research grants and professional and patient symposia on multiple myeloma and related blood cancers. MMRF publishes a quarterly newsletter and provides referrals and information packets free of charge to patients and family members.

Oral and Head and Neck Cancer

Contact Information	Description
Support for People With Oral and Head and Neck Cancer, Inc. (SPOHNC) PO Box 53 Locust Valley, NY 11560–0053 Tel: 1–800–377–0928 http://www.spohnc.org e-mail: info@spohnc.org	SPOHNC is a not-for-profit national organization founded in 1991 to address the emotional, physical, and humanistic needs of people who have oral cancer and head and neck cancer.

Pancreatic Cancer

Contact Information	Description
Pancreatic Cancer Action Network (PanCAN) PO Box 1010 Torrance, CA 90505 Tel: 1–877–2–PANCAN (1–877–272–6226) http://www.pancan.org e-mail: information@pancan.org	PanCAN, a nonprofit advocacy organization, educates health professionals and the general public about pancreatic cancer to increase awareness of the disease. PanCAN also advocates for increased funding of pancreatic cancer research and promotes access to and awareness of the latest medical advances, support networks, clinical trials, and reimbursement for care.

Prostate Cancer

Contact Information	Description
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	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. It provides information on urologic disease and dysfunction including prostate cancer treatment options, bladder health, and sexual function. AFUD also offers prostate cancer support groups through its Prostate Cancer Network. Some Spanish-language publications are available.
CaP CURE (Association for the Cure of Cancer of the Prostate) 1250 Fourth Street, Suite 360 Santa Monica, CA 90401 Tel: 1–800–757–CURE (1–800–757–2873) http://www.capcure.org e-mail: capcure@capcure.org	CaP CURE is a nonprofit organization that provides funding for research projects to improve methods of diagnosing and treating prostate cancer. It also offers printed resources for prostate cancer survivors and their families. The mission of CaP CURE is to find a cure for prostate cancer.
Us Too! International, Inc. 5003 Fairview Avenue Downers Grove, IL 60515 Tel: 630–795–1002 (in the Chicago area) 1–800–80–US TOO (1–800–808–7866) http://www.ustoo.org e-mail: ustoo@ustoo.com	Us Too! is a prostate cancer support group organization. Goals of Us Too! are to increase awareness of prostate cancer in the community, educate men newly diagnosed with prostate cancer, offer support groups, and provide the latest information about treatment for this disease. A limited selection of Spanish-language publications is available.

Skin Cancer and Melanoma

Contact Information	Description
Melanoma Education Foundation 7 Jones Road Peabody, MA 09160 http://skincheck.com e-mail: MEF@skincheck.org	This Web site provides information about melanoma, emphasizing the importance of monthly self-examination of the skin to detect melanoma while it is thin and curable.
The Melanoma Patients' Information Page PO Box 38 Cloverdale, CA 95425 http://www.mpip.org e-mail: admin@mpip.org	Designed for melanoma patients and melanoma investigators, this Web site includes published results of clinical trials in chemotherapy, vaccines, and gene therapy. It also has a database of research abstracts and a bulletin board for questions and answers.
The Melanoma Research Foundation 23704-5 El Toro Road, 206 Lake Forest, CA 92630 Tel: 1–800–673–1290 http://www.melanoma.org/ e-mail: mrf@melanoma.org	The Foundation supports medical research for the treatment of melanoma and acts as a resource for melanoma patients, their families, and friends.
The Skin Cancer Foundation PO Box 561 New York, NY 10156 Tel: 1–800–SKIN–490 (1–800–754–6490) http://www.skincancer.org e-mail: info@skincancer.org	Major goals of The Skin Cancer Foundation are to increase public awareness of the importance of taking protective measures against the damaging rays of the sun and to teach people how to recognize the early signs of skin cancer. The Foundation conducts public and medical education programs to help reduce the incidence of skin cancer.

Employment and Legal Rights for Cancer Survivors

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 Rehabilitation Act of 1973 and the Americans With Disabilities Act (ADA) of 1990 protect people against employment discrimination based on a disability. These laws often cover cancer survivors.

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 or her employees with disabilities.

Disability and Discrimination (continued)

Contact Information	Description
U.S. Department of Justice (DOJ) 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.
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 or her job.

Legal Assistance

Contact Information	Description
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.
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 your 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.

Other Legal Information

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	You can contact ACS for legal information.

Other Legal Information (continued)

Contact Information	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 has information on a wide range of cancer topics, including employment issues.
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.canceradvocacy.org e-mail: info@canceradvocacy.org	The NCCS provides cancer information, including a book titled *Working It Out: Your Employment Rights as a Cancer Survivor.*

Tell Us What You Think...

To order more copies of this book, call
1–800–4–CANCER
(1–800–422–6237)

Look for other books in the *Facing Forward Survivor Series...*

Available Now:

- ***Life After Cancer Treatment***
- ***Siga adelante: la vida después del tratamiento del cáncer***

Available in 2004:

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

Please tell us what you think about this book.

1. This book 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 book to another person
____ not recommend this book to another person

5. I received this book from:
____ a doctor, a nurse, or other health professional
____ an information rack at a cancer center, hospital, or doctor's office
____ National Cancer Institute
____ another cancer group/organization (which one:__________________)
____ other (please explain: ____________________________)

6. I am: ☐ a cancer survivor
☐ a family member or friend of someone treated for cancer
☐ a health professional ☐ other__________________

7. What is your age? ______

8. Did this book help you:

a) learn about the different ways you can "make a difference" in cancer?	☐ yes ☐ no
b) understand how you can benefit by taking part in cancer-related activities?	☐ yes ☐ no
c) learn about how you can get started in cancer-related activities?	☐ yes ☐ no
d) learn how you can contact organizations through which you can "make a difference"?	☐ yes ☐ no

9. In the next six months, how likely are you to take part in cancer-related activities?
☐ very likely ☐ somewhat likely ☐ not very likely ☐ already do

Thank you very much for your feedback.

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