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CANCERCARE[®]

Coping With Cancer: Tools to Help You Live

WWW.CANCERCARE.ORG

The CancerCare Connect® Booklet Series offers up-to-date, easy-to-read information on the latest treatments, managing side effects, and coping with cancer.

To order free copies of this booklet, please use the online order form on our website, www.cancercare.org.



CancerCare® helps individuals and families better cope with and manage the emotional and practical challenges arising from cancer. Our services—for patients, survivors, loved ones, caregivers, and the bereaved—include counseling and support groups, educational publications and workshops, and financial assistance. All of our services are provided by professional oncology social workers and are offered completely free of charge. CancerCare is a national nonprofit organization founded in 1944.

CancerCare relies on the generosity of supporters to provide our services completely free of charge to anyone facing a cancer diagnosis. If you have found this resource helpful and wish to donate, please do so online at www.cancercare.org/donate. You may also mail a check, payable to CancerCare, to CancerCare®, Attn: Donations, 275 Seventh Avenue, New York, NY 10001. Thank you.

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Coping With Cancer: Tools to Help You Live

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Created by CancerCare®

Introduction

What do I tell my family? Am I going to be able to continue working? How do I pay for treatment? What happens after my treatment is finished?

The answers to these questions are different for everyone because no two people experience cancer in the same way. A cancer diagnosis may make you feel worried, sad, confused, or angry. Your world is now filled with information and medical terms you never thought you needed to learn. And in addition to the physical difficulties, there are emotional and financial issues that you must learn to manage. Without a doubt, cancer turns your world upside down.

This booklet will help you understand the challenges that are a part of living with cancer and provide you with the tools you need to cope better with this experience. Importantly, you will learn that you are not alone—there are sources of support available to you, and many people have made this journey before you.

Since 1944, CancerCare® has provided free, professional support services to individuals, families, caregivers, and the bereaved to help them better cope with and manage the emotional and practical challenges arising from cancer. Our services include counseling and support groups, educational publications and workshops, and financial assistance. All of our services are provided by professional oncology social workers and are offered completely free of charge.

Our professional oncology social workers know that when someone is first diagnosed, it seems overwhelming. From the moment of diagnosis, life will never be the same. But the tips and advice outlined in this booklet will give you the tools you need to live with cancer.

Treating the Whole Person

When someone is diagnosed with cancer, it seems everyone is focused, and rightly so, on the person's physical well-being, including treatments, side effects, doctor's visits, and follow-up tests. But we know there are other parts of life affected by cancer: self-image, work, family, friendships, and approach to living.

Some patients may feel that they are complaining if they express sadness at losing their hair because of treatment. They may think they should just be glad to be alive and that worrying about a "little thing" like hair loss shouldn't be a concern. However, there is nothing wrong with being concerned with these issues too.

Experts agree that the standard of care for all cancer patients must include addressing the emotional and practical concerns after a diagnosis. CancerCare is one of the leaders in providing psychosocial services. Our social workers understand the complex issues raised by cancer. More importantly, we know that finding ways to cope with these concerns brings an enormous sense of relief to both the person with cancer and his or her loved ones.



Coping: What It Really Means

People sometimes mistakenly think that coping means just living with a problem, whether you like it or not. But coping actually means managing a problem and finding ways to take control of it. You can't control the fact that you or a loved one has cancer. But you can control how you react to and live with cancer.

What Is Coping?

Coping Is...

- Managing and understanding what you need to improve your situation
- Making efforts to bring your problems under control
- Maintaining a healthy balance between realism and cautious optimism

Coping Is Not...

- Hopeless acceptance of a problem
- Being happy about your whole life all the time in spite of problems
- A hands-off attitude that says you don't have to make an effort to overcome problems

Learning About Medicine

One of the biggest challenges for people with cancer is sorting through treatment options. As the science of treating cancer has advanced, researchers have developed better, more effective treatments, which means patients have more choices than they did a few decades ago.

At CancerCare, we often hear patients say they are not sure how to choose the “right” treatment. They worry that making the “wrong” choice could make their condition worse.

They may feel overwhelmed by the vast amount of information available on the Internet. Advertisements on television and health stories in newspapers and magazines add to this outpouring of information. It’s difficult to sift through everything. Add to that mix the many different health care professionals involved in your care, along with well-meaning friends and family offering opinions, and it all adds up to what some people with cancer describe as “too many voices.”

People with cancer know they are expected to take part in care and treatment decisions. Since treatment often takes place in an outpatient setting, it allows for greater freedom. However, it also means that patients and their loved ones will spend less time with doctors and nurses and more time taking greater responsibility for their own care. So how do you cope with this situation? Here are some tips:

Recognize that as a health care consumer, it is your right to have a good health care team that listens to your questions and concerns. Get to know all the members of your team and learn how each one helps you.

How to Find Credible Information on the Web

The information found on the Internet is not a substitute for medical care. The credible information you find on the Web should be used to help you communicate more effectively with your doctor. For a list of trusted websites, see the resources at the end of this booklet. But here are some tips on how to identify credible Internet resources:

Identify the purpose of the website. Is it educational or commercial? For example, a website sponsored by a pharmaceutical company isn't likely to give you unbiased information about a competing drug. But because that site must meet the standards of the U.S. Food and Drug Administration, it will be an excellent source on a particular product.

Find the source of the information. Generally, nationally known cancer centers, medical schools, large nonprofit organizations, and government agencies provide the highest quality information.

Locate the contact information for the people who developed the website. If you can't communicate with them, find another source.

Identify one person on the medical team who is in charge of your care and "funnel" all information through that person.

As you visit different websites or hear about new treatments, write down questions as they arise. At your



next medical appointment, bring these questions with you so you can keep track of what you need to know.

During your medical appointments, take notes or ask a family member to take notes. Also, ask your doctor whether you can tape record your visits. This will allow you to go back later and listen carefully to all the information presented by your doctor.

Ask your doctor or other medical professional to recommend books, brochures, and websites. For tips on evaluating websites, see the sidebar on the left.

Find trustworthy educational programs about your cancer. CancerCare offers free Connect Education Workshops™, which provide people with reliable information from experts on a range of cancer diagnoses and topics. Visit our website www.cancercare.org to see a schedule of upcoming programs or to listen to past programs.

Finding Financial Help

Cancer is an expensive illness. Many of the people who contact CancerCare each year cite financial need as a major source of difficulty. Some patients have no health insurance, and some are insured but don't have coverage for parts of their treatment such as prescription drug co-payments. Many patients do not have the extra income to meet the new treatment-related costs, including child care or transportation to treatment centers. All the while, people with cancer and their caregivers often have to cut back on the time spent at work, which means their income decreases at the same time that their bills pile up.

Financial stress often causes emotional stress. For example, when a family is under new financial pressures, it can create



feelings of worry, sadness, and anxiety. Because cancer treatment often includes years of medical care, financial concerns can influence major life decisions about working, housing, and schooling.

There is assistance available, and CancerCare can help you navigate the maze of government, nonprofit, and pharmaceutical programs, as well as other sources of financial help. Here are some of the things you can do:

Talk to your insurance company. Many companies will assign a case manager to help you work through insurance concerns, clarify benefits, and suggest ways to get other health services.

Talk to your health care providers about your needs. Many treatment centers have social workers who help you sort through financial concerns. CancerCare social workers can also help you.

Find out which government programs (entitlements) you are eligible for, and apply promptly. To contact the Social Security Administration, call 800-772-1213 or visit www.ssa.gov. To contact the Centers for Medicare & Medicaid Services, call 800-633-4227 or visit www.cms.gov. For Medicaid information, contact local listings for a Medicaid office in your state.

Learn how private organizations can help you. There are nonprofit programs for co-pay relief, as well as pharmaceutical patient assistance programs to help those who do not qualify for other aid. See our listing of financial assistance resources at the end of this booklet.

Dealing With the Emotional Impact

The words “you have cancer” can be frightening and overwhelming. Some people experience feelings of helplessness and hopelessness and question whether they know how to deal with these feelings. At times, people may be reluctant to tell their doctor about their concerns because they don’t want to distract him or her from the primary goal of treatment.

Emotional needs vary from person to person, depending on age, support from family and friends, access to medical care, and other factors. For example, a 25-year-old person with a cancer diagnosis has different pressures and responsibilities than a person who is 60. Younger people may feel more confusion about having cancer at an age when they usually feel invincible. On the other hand, an older person may have fewer family members to rely on. If they have children, they may have moved away and started their own families, or there may be no spouse at home to help care for their medical needs.

But no matter what our stage in life, cancer takes an emotional toll on the person diagnosed, as well as everyone close to that person. At CancerCare, we work to individualize support for each person, offering help that fits his or her needs. It’s important to remember that everyone experiences some kind of sadness or helplessness when confronted with cancer—and that many people have come through these experiences. Life will never be the same after cancer, but it doesn’t mean you stop living. There are many things you can do to handle the emotional impact of cancer. To cope better emotionally, you can:

Keep track of your feelings. Many people find it helpful to keep a journal or record their emotions through photography, drawing, painting, music, or other forms of expression.

Share your feelings with people close to you. Sometimes, caregivers and people with cancer feel as if they are a burden to their loved ones by complaining about their problems. Remember that you are entitled to every emotion you have. Don't be afraid to share these emotions with the people close to you.

Seek individual counseling with a professional. Oncology social workers, psychologists, and psychiatrists help you sort through your many complex emotions. CancerCare provides free individual counseling to people with cancer and caregivers across the country.

Join a support group. Talk with someone who has had a similar experience. Support groups help you feel less isolated. They provide reassurance, suggestions, and insight, allowing you to share similar concerns with your peers in a safe and supportive environment. CancerCare provides free, professionally led support groups over the telephone, online, and face-to-face.

Tell your doctor and nurse about your feelings. Doctors understand, better than ever before, that patients are concerned about good quality of life as they go through treatment. Sometimes, people benefit from a referral for counseling or treatment for anxiety or depression.

Strengthening the Spirit

When you or a loved one is diagnosed with cancer, you might find yourself turning to your spiritual side more often to help you cope. Or you may begin to question your faith. Both of these reactions are normal. Whether you are in the process of strengthening or reevaluating your spiritual beliefs, you might want to try the following:

Take time to meditate or pray regularly. This can bring a sense of calm and stability during difficult times.

Read spiritual writings such as the Bible, the Koran, Bhagavad Gita, or other faith-based texts. Delving into sacred texts can put you in touch with ancient traditions of wisdom and give you a sense of connection with a more divine reality. Recently published books on spirituality can also give new insights.

Seek the help of others. You might begin an ongoing dialogue with your clergy or counselor or join a group for meditation, prayer, and support.

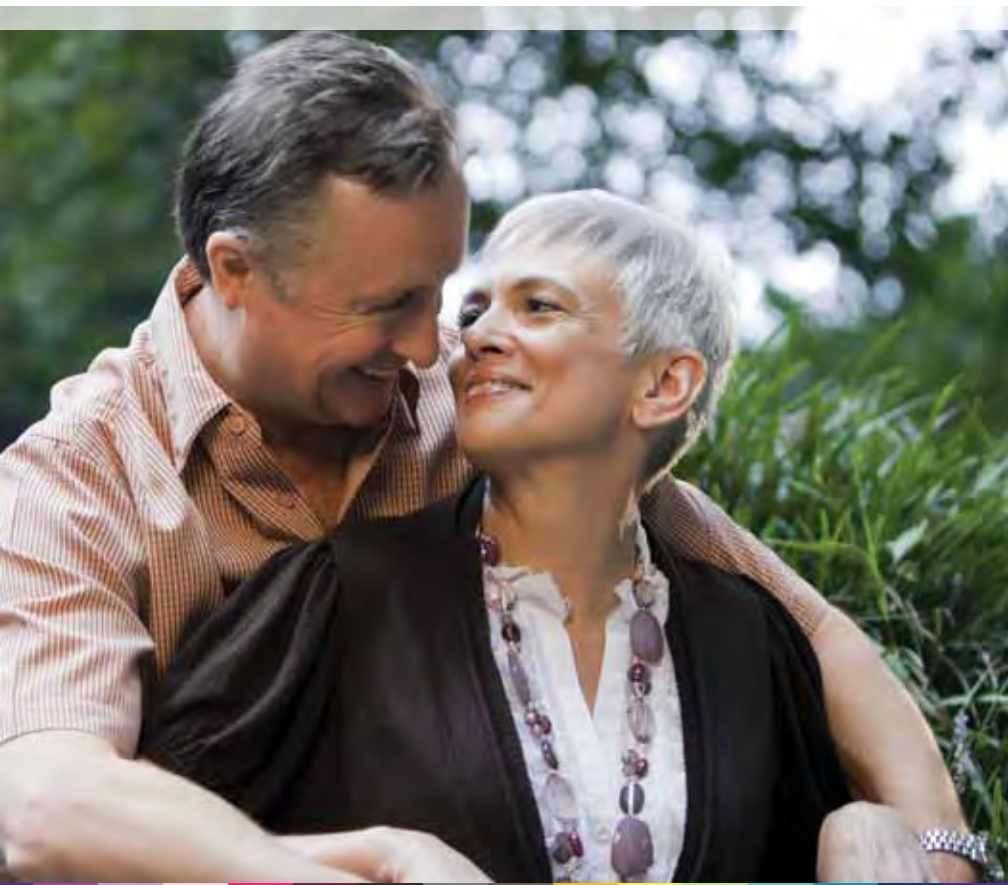
Find a place to retreat. You may find that visiting places such as natural settings or concerts or museums may help you cultivate a sense of peace. Also try listening to soothing music to help you quiet your mind and reflect.

Keep a journal to express your feelings, thoughts, and memories. It can contribute to your process of self-discovery and spiritual development.

Your Inner Power

Life changes in many ways when you or a loved one is diagnosed with cancer. The educational, financial, and emotional challenges are great. But there is one thing that even cancer does not have the power to change: You are the expert on your own life.

You can manage many aspects of cancer, which will help you cope better with the challenges that come up. CancerCare and the organizations listed among the resources at the back of this booklet may give you help and support along the way.



Frequently Asked Questions

Q. My wife was diagnosed with cancer, and we have two young children at home. How do we explain her illness to them?

A. With young children, there may be a temptation to avoid discussing serious illnesses like cancer. You may not want to burden your children with all the complex worries of the disease. But the best thing you can do for them is to give them accurate, age-appropriate information about cancer. Don't be afraid to use the word "cancer" and tell them where it is in the body. If children don't get this information from their parents, they will often invent their



own explanations, which are often more frightening than the facts. For example, they may think that they did something wrong to cause the cancer.

It's helpful to explain the treatment plan and what this will mean to them. For example, "Dad will bring you to soccer practice instead of Mom." Prepare your children for any physical changes you might encounter in treatment. Remember that whatever emotions your children are experiencing are normal, and they should be encouraged to express and share these emotions with you and other trusted adults.

CancerCare's professionally trained oncology social workers can help you and your family cope with the effects of a cancer diagnosis on the family.

Q. I know I'm supposed to eat well during treatment, but the chemotherapy makes me feel nauseated, and I don't have an appetite. What can I do?

A. Nausea is a common side effect of cancer treatment, but it can be managed with the help of your doctor and anti-nausea medications. Also, there are some things you can do on your own to get relief:

- Avoid strong food odors, which can bring on nausea.
- Rinse your mouth often to eliminate any bad taste.
- Explore how your taste buds may have changed. Determine what foods taste good to you now.
- Wear loose-fitting, comfortable clothing.
- Distract yourself with music, television, or other activities you enjoy.



Q. I am a single person living alone, and I'm worried that when I start treatment, I won't have the strength to perform basic tasks, like cooking or dressing. I have friends, but they all have their own busy lives. How do I get help?

A. For people with cancer who are living alone, daily chores and tasks can be especially burdensome. Perhaps you don't want to bother your friends or ask them to do simple tasks because it makes you feel helpless. But most of the time, friends are looking for a way to contribute to your care, even if they can't be there all the time. Try appointing one friend to be your primary caregiver, and have that person organize help from your other friends. Together, they can work as a team to bring your meals, do your laundry, or water the lawn. Having a specific task allows each friend to feel he or she is helping you in a meaningful way.

Home care assistance may also be available through your hospital, nonprofit agencies, and private organizations. Many

times, home care costs are covered by insurance, if part of the care involves administering medical treatment. See our list of resources for home care at the end of this booklet.

Q. I'm a caregiver and will need to take time off from my job to care for my loved one. Things are tough enough as it is, and with more medical costs, I'm afraid of being fired and losing income. What rights do I have in the workplace?

A. The Family Medical Leave Act of 1993 (FMLA) gives you the right to take time off if you are ill or caring for an ill dependent, without losing your job. This law:

- Applies to employers with 50 or more employees.
- Can be used to provide medical leave for people with illness such as cancer or family leave for caregivers.
- Provides 12 weeks of unpaid leave for serious illness. You don't have to take the 12 weeks all at once; you can take time in blocks, such as several hours a day.
- Allows you to use accrued paid annual leave or possibly accrued sick leave during your family or medical leave.
- Defines family members as your parent, child (including adult children who are unable to care for themselves), or spouse.
- Allows your employer to request medical certification by a doctor or other health care provider.

To learn more about the FMLA, talk to your department of human resources or see our list of resources on the back two pages of this booklet.

Q. My husband was just diagnosed with metastatic cancer. We're told that he has a very poor prognosis, and we don't know what to do. Should we go for the most aggressive treatment or seek end-of-life care?

A. Facing mortality and the possibility of death from cancer is one of the most difficult things to do. A first reaction may be to try everything medically possible. As with any treatment decision, patients and family members often feel anxious and uncertain. In the end, you must make the decision that is right for your family and that will honor the wishes of the patient. This can only happen through open communication with your loved ones and your health care team. Nobody wants to talk about death, but studies have shown that clear communication reduces distress, resolves problems, and strengthens coping.



End-of-life care is when the goal of care shifts from cure to comfort. In this mode, your health care team works to control the person's pain and other symptoms (called palliative care) and also to provide supportive and spiritual guidance. It does not mean that you've "given up" on the person, but rather that you are facing the inevitability of death and want to make the person as comfortable as possible.

End-of-life care can also give the person with cancer and family members the opportunity to reflect together and reconcile some of their memories, sadness, and complex emotions in this final time together.

For a list of end-of-life resources, look under "Hospice and Palliative Care" on the last page of this booklet.

GENERAL CANCER INFORMATION

CancerCare®

800-813-HOPE (4673)
www.cancercares.org

American Cancer Society

800-227-2345
www.cancer.org

Cancer.Net

Patient information from the American Society of Clinical Oncology
888-651-3038
www.cancer.net

National Cancer Institute

800-422-6237
www.cancer.gov

National Comprehensive Cancer Network

The patient website of this nonprofit alliance provides free treatment summaries and guidelines for various diagnoses
www.nccn.com

CLINICAL TRIALS

Coalition of Cancer Cooperative Groups

866-772-9897
www.CancerTrialsHelp.org

National Cancer Institute

800-422-6237
www.cancer.gov/clinicaltrials

FINANCIAL ASSISTANCE

CancerCare

800-813-HOPE (4673)
www.cancercares.org

CancerCare Co-Payment Assistance Foundation

866-55-COPAY (26729)
www.cancercarescopay.org

Cancer Financial Assistance Coalition

www.cancerfac.org

Partnership for Prescription Assistance

888-477-2669
www.pparx.org

Resources

EMPLOYMENT AND LEGAL RIGHTS

Cancer and Careers
www.cancerandcareers.org

**Cancer Legal Resource
Center**
866-843-2572
www.cancerlegalresourcecenter.org

**Patient Advocate
Foundation**
800-532-5274
www.patientadvocate.org

PEER MATCHING

Cancer Hope Network
800-552-4366
www.cancerhopenetwork.org

Cancer Support Community
888-793-9355
www.cancersupportcommunity.org

Imerman Angels
877-274-5529
www.imermanangels.org

HOME CARE

**National Association for
Home Care & Hospice**
202-547-7424
www.nahc.org

**U.S. Department of Health
and Human Services
Administration on Aging**
800-677-1116
www.aoa.gov

HOSPICE AND PALLIATIVE CARE

**Center to Advance
Palliative Care**
www.getpalliativecare.org

**Hospice Foundation of
America**
800-854-3402
www.hospicefoundation.org

**National Hospice and
Palliative Care Organization**
800-658-8898
www.nhpco.org
www.caringinfo.org

LODGING

Joe's House
877-563-7468
www.joeshouse.org

**National Association of
Hospital Hospitality Houses**
800-542-9730
www.nahhh.org

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WWW.CANCERCARE.ORG

800-813-HOPE (4673)