

COPING WITH CANCER

Tools to Help You Live

CANCERCARE CONNECT® BOOKLET SERIES



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Coping With Cancer: Tools to Help You Live

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

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Founded in 1944, CancerCare® is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include case management, counseling and support groups over the phone, online and in person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by master's-prepared oncology social workers and world-leading cancer experts.

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.

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What do I tell my family? Will I 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 has changed and is now filled with information and medical terms you never thought you needed to learn. 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 that can help you cope better with this experience. You will learn that you are not alone—there are sources of support available to you.



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 especially as it pertains to treatments, side effects, doctor's visits and tests. There are many aspects of your life that are affected by a diagnosis. For instance, cancer can impact your self-image, work, family, friendships and how you go about living life.

Experts agree that the standard of care for all cancer patients must include not only addressing the practical impact on the individual, but also how the diagnosis affects a person's emotional and spiritual well-being. CancerCare's oncology social workers understand the complexity of issues raised by cancer. More importantly, social workers know that finding ways to cope with these concerns can bring an enormous sense of relief to both the person with cancer and their loved ones.

The Value of Oncology Social Workers

Oncology social workers are professionals who provide emotional support to people with cancer. Oncology social workers can help individuals living with cancer access practical assistance as well.

Oncology social workers provide individual counseling, facilitate support groups and identify resources that can help with home care or transportation. They can offer guidance and help people navigate the process of applying for Social Security disability or other forms of assistance. CancerCare's oncology social workers are available to help people, free of charge. People can access support through case management, individual, counseling and support groups.

Coping: What It Really Means

People sometimes mistakenly believe that “coping” with cancer simply means living with a problem, whether you like it or not, but coping actually means finding ways to adapt to a diagnosis. You can’t control the fact that you or a loved one has cancer, but you can manage how you respond 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

Counseling to Better Cope With a Cancer Diagnosis

Oncology social workers can help you find ways to cope with the stress of a cancer diagnosis. They can provide guidance and help you and your loved one through the experience of living with cancer. Seeking professional counseling is a strength and a good way to help you cope when you are feeling overwhelmed and attempting to adjust to a cancer diagnosis. Individual counseling provides a safe space to share and examine situations that you may discover yourself challenged by.

Learning About Treatment

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 and more effective treatments. This means patients have more choices than they did a few decades ago or even a few years ago.

One of the reasons why making choices can so often be overwhelming and confusing is the vast amount of information that is available. Some of the information may be unreliable. Advertisements on television, health stories, literature available on the internet, newspapers and magazines add to the flood of information. It can be difficult to sift through everything. All this, in conjunction with your health care team and well-meaning friends and family offering opinions, can contribute to the stress people experience at times.



Here are some tips to help you better communicate with your health care team:

- 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.
- 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 if you can 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 to recommend additional resources and information on your diagnosis and treatment. For tips on evaluating websites, see the sidebar on the right.
- Find trustworthy educational programs about your cancer. CancerCare offers free educational materials from experts on a range of cancer diagnoses and topics. Visit www.cancercare.org to view all of CancerCare’s resources.

How to Find Credible Information on the Internet

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. 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.

Finding Financial Help

Living with cancer can be expensive. Some people may have no health insurance; others may be insured but don't have coverage for aspects of their treatment, such as prescription drug co-pays. Many people do not have the needed income to meet new costs such as child care or transportation to treatment. People with cancer and their caregivers often have to cut back on time spent at work, which often affects their income at the same time that their bills are building up.

Financial stress often causes emotional stress. For example, when a family is under financial pressures, it can create feelings of worry, sadness and anxiety. Because cancer treatment often means years of medical care, financial concerns can influence major life decisions about work, housing and school. There is assistance available, and CancerCare can help you navigate the maze of government, nonprofit and co-pay assistance programs, as well as other sources of financial help. Here are some of the things you can do:

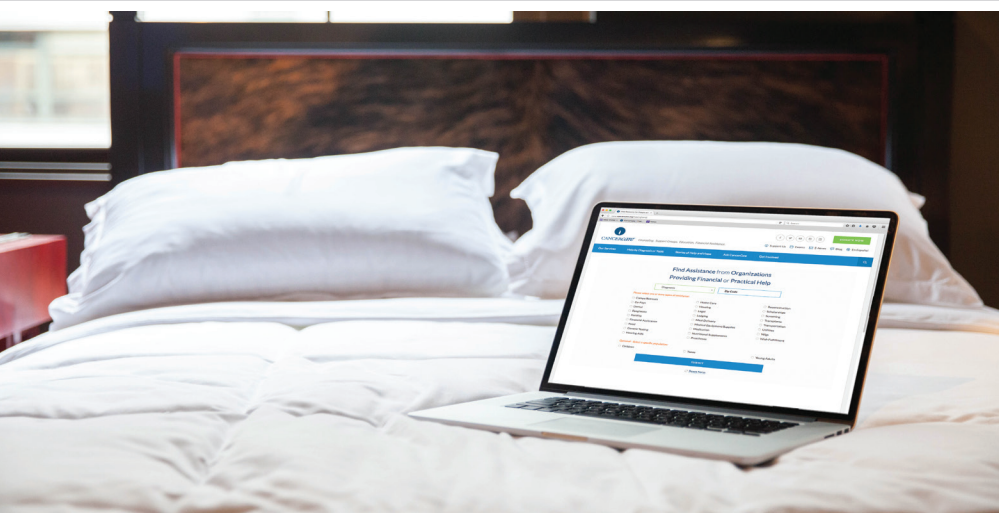
Talk to your insurance company. Most companies will assign a case manager to help you work through insurance concerns, clarify benefits and suggest ways to get other health services.

Talk to your health care providers about your needs. Many treatment centers have social workers who help you sort through financial concerns. A CancerCare oncology social worker 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 organizations can help you. There are nonprofit programs for co-pay relief that can help those who do not qualify for other aid. To learn more, read CancerCare's fact sheets titled "Sources of Financial Assistance" and "How Co-Payment Assistance Foundations Help."

CancerCare's Online Helping Hand. CancerCare's Online Helping Hand (www.cancercare.org/helpinghand) is a searchable, online database of financial and practical assistance available for people with cancer. This comprehensive online tool features up-to-date contact information and descriptions for hundreds of national and regional organizations offering financial help to people with cancer. You can search by diagnosis, zip code and type of assistance.



Tips for Taking Control of Your Finances

When you or a loved one has received a cancer diagnosis, money may be the last thing you want to think about, but taking control of your finances from the start may be the best way to prevent a crisis later on.

Keep track of important papers. Many people find it helpful to keep their records and paperwork in one place for easy reference. Important documents may include copies of medical records and prescription information.

Get a handle on your income and expenses. Figure out how much money is coming in to your household, how much you spend and what you spend it on. Do you have money saved for an emergency? Do you have assets (a home, other property, a retirement plan, life insurance) that you can use to obtain cash? Have you elected a power of attorney?

Stay on top of medical bills. The consequences of medical debt are staggering and unfortunately all too common. Medical debt can be a major burden and a source of continuing stress for many living with cancer. If you find yourself behind on paying medical bills, there are resources that can help. View the Resource Section at the end of this booklet.

Get help. Oncology social workers are licensed professionals who counsel people affected by cancer, providing emotional support and helping people access practical assistance.

Coping 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 talk to their doctor about their concerns because they don’t want to distract them from the primary goal of treatment.

Emotional needs vary from person to person, depending on age, closeness of 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 experience more confusion over having cancer at an age when they usually feel invincible and none of their friends are ill. On the other hand, an older person may have fewer family members to rely on who can help care for their medical needs.

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 with each individual, offering support that meets each person’s needs and concerns. It’s important to remember that everyone experiences some kind of sadness or helplessness when confronted with cancer—and that many people learn to cope and adapt to these experiences. Remember that there are many things you can do to adjust to the emotional impact of cancer. To help you cope more effectively while undergoing treatment, you could try the following:

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. You may feel that the diagnosis is yours alone to cope with, and perhaps feel the need to isolate yourself from others. 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 in New York and New Jersey as well as case management services across the country.

Join a support group. Support groups provide an environment where someone affected by cancer does not have to explain what they are going through because the other group members will understand. In addition to lessening one’s sense of isolation, support groups can be a source of valuable information. Not surprisingly, members find that sharing resources and coping skills can be highly rewarding, whether on the giving or the receiving end of the transaction. CancerCare provides free, professionally led support groups over the telephone, online and face-to-face.

Tell your doctor and nurse about your feelings. Health care professionals understand 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 are diagnosed with cancer, you might find yourself turning to your spiritual side more often to help you cope. You may begin to question your faith. 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 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.
- Reach out to your clergy or spiritual counselor, or join a group for meditation, prayer and support.
- Retreat to spiritual spaces, such as natural settings or houses of worship, or listen to soothing music to cultivate a spiritual sense of peace.
- Engage in a meditation or prayer group.
- Keep a journal to express your feelings, thoughts and memories. It can contribute to your process of self-discovery and spiritual development.

CancerCare Can Help

Receiving a diagnosis of cancer can be very difficult and adjusting to the necessary changes in your life can be extremely challenging.

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and provide information on support groups and other resources. To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit www.cancercare.org.

In addition, you will build a personal support network during this time which may be comprised of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. It can be helpful to designate certain responsibilities and roles to family and friends. Identify family strengths and match the task to those strengths—for instance, ask a family member who loves to shop to pick up something for you at the store, or you could ask a friend who's a good listener to come over for a chat.

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 often can be more frightening than the reality. For example, children 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 instance, "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 specialized services for children affected by cancer help parents and children cope with the effects of cancer 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 in 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 they are helping you in a meaningful way.

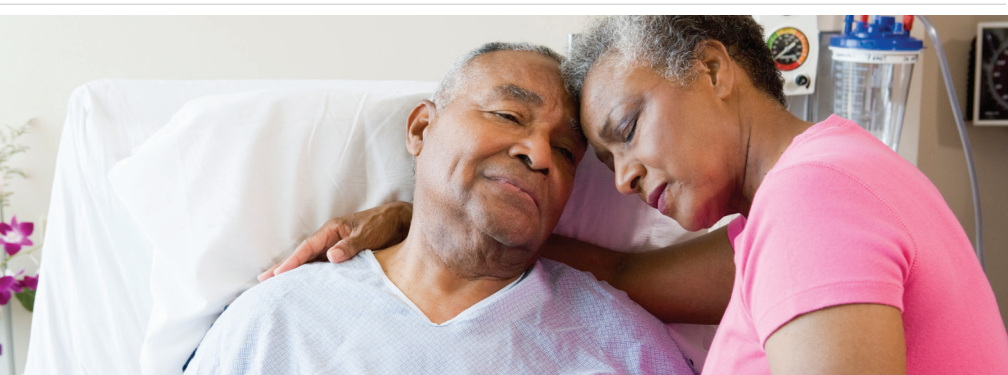
Home care assistance is also available through your hospital, nonprofit agencies, and private organizations. Many times, home care costs are covered by insurance, if the care involves administering medical treatment. See our list of resources for home care at the end of this booklet.

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 and 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 your spouse.
- Allows your employer to request a 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 at the end of this booklet.



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

A: It is important that you and your family make the decision that is right for you. Honoring our choices and wishes either at the end-of-life or whether we decide to undergo treatment can help us cope. Facing our mortality and trying to decide whether or not end-of-life care is the best thing for us can be one of the most difficult decisions to make in our lives. A reaction people may harbor is to first try everything that is medically possible. As with any major treatment decisions, patients and family members can experience a great deal of anxiety and uncertainty. This is normal and to be expected. Nobody likes to think or talk about end-of-life concerns, yet studies have shown that open communication between you, your loved ones and your health care team reduces distress, helps to alleviate burden of having to make the decision alone and strengthens our capacity to cope.

The focus of end-of-life care is on comfort and the person's quality of life. End-of-life care centers on managing the person's physical, emotional and spiritual well-being during this period. End-of-life care not only addresses issues surrounding pain management but affords emotional and spiritual support as well. Opting for end-of-life care does not mean that you've "given up," but instead are embracing the inevitability of death. It is a decision the focuses on quality of a person's life at the end of life. End-of-life care also gives the person with cancer and family members an opportunity to reconcile and reflect on some of the memories, feelings of sadness and an array of complex emotions may emerge during this time together. For a list of end-of-life resources, please see the end of this booklet.

Resources

Medical Information

American Cancer Society

800-227-2345
www.cancer.org

Cancer.Net

888-651-3038
www.cancer.net

National Cancer Institute

800-422-6237
www.cancer.gov

Supportive Resources

CancerCare

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

Cancer Hope Network

800-467-3638
www.cancerhopenetwork.org

Imerman Angels

877-274-5529
www.imermanangels.org

Caregiver Action Network

202-454-3970
www.caregiveraction.org

Financial Assistance Resources

CancerCare

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

CancerCare Co-Payment Assistance Foundation

866-55-COPAY (866-552-6729)
www.cancercarecopay.org

Chronic Disease Fund

877-968-7233
www.mygooddays.org

Healthwell Foundation

800-675-8416
www.healthwellfoundation.org

Partnership for Prescription Assistance

888-477-2669
www.pparx.org

Patient Access Network Foundation

866-316-7263
www.panfoundation.org

Patient Advocate Foundation Co-Pay Relief Program

www.copays.org

Patient Services Incorporated

800-366-7741
www.patientservicesinc.org

For Employment and Legal Rights

Cancer Legal Resource Center

866-843-2572
www.cancerlegalresources.org

National Partnership for Women & Families

202-986-2600
www.nationalpartnership.org

Patient Advocate Foundation

800-532-5274
www.patientadvocate.org

Home Care Resources

National Association for Home Care & Hospice

202-547-7424
www.nahc.org

U.S. Administration on Aging

800-677-1116
www.aoa.gov

Hospice and End-of-Life Resources

American Academy of Hospice and Palliative Medicine

www.aahpm.org

Compassion & Choices

800-247-7421
www.compassionandchoices.org

National Association for Home Care and Hospice

www.nahc.org

National Hospice and Palliative Care Organization

800-658-8898
www.nhpco.org

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