



CANCERcare
Connect[®]

Coping With Cancer: Tools to Help You Live

Presented by

Rosalie Canosa, LCSW-R, MPA
CancerCare

Learn about:

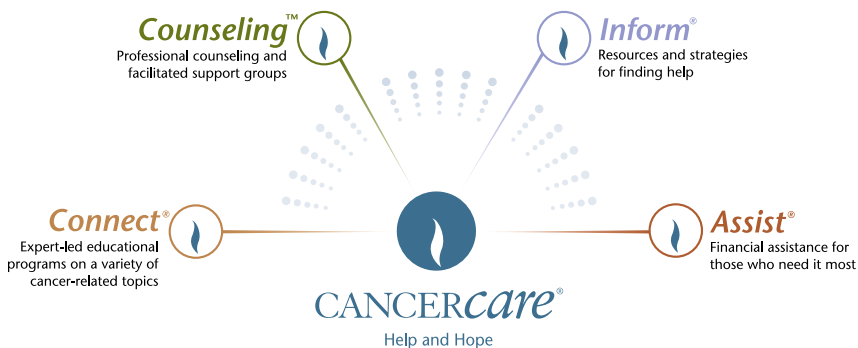
- Living with cancer
- Researching your cancer and treatment
- Finding financial help
- Emotional concerns and cancer
- Coping tips and helpful resources



CANCERcare[®]

Help and Hope

The *CANCERcare*[®] Constellation of Services



CancerCare's services are provided free of charge to anyone affected by cancer

1-800-813-HOPE (4673) • www.cancercares.org

CancerCare is a national nonprofit organization that provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs—including counseling, education, financial assistance, and practical help—are provided by trained oncology social workers and are completely free of charge. Founded in 1944, CancerCare provided individual help to more than 97,000 people last year and received nearly 2.1 million visits to its websites. For more information, call 1-800-813-HOPE (4673) or visit www.cancercares.org.

Contacting CancerCare

National Office

CancerCare
275 Seventh Avenue
New York, NY 10001
E-mail: teled@cancercares.org

Administration

Tel: 212-712-8400
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Website: www.cancercares.org

Services

Tel: 212-712.8080
1-800-813-HOPE (4673)

If you are a health care professional interested in ordering free copies of this booklet for your patients, please use the online order form on our website, www.cancercares.org.

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Program Division Director

CancerCare

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Cancer changes everything.

What do I tell my children? How is my husband going to react? 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. The **diagnosis** may make you feel worried, sad, confused, or even angry. Your new world is filled with information and medical terms you never wanted 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 CancerCare Connect® 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.

For more than 60 years, CancerCare®—a national non-profit organization—has helped people with cancer and their loved ones with exactly these kinds of challenges. We provide professional counseling, educational programs, financial

guidance, and referrals to helpful resources—all completely free of charge. Our **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 tools you need to truly *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: treatments, side effects, doctor visits, tests. But we know there are other parts of life affected by cancer: your self-image, work, family, and your approach to living. These are the **psychosocial aspects** of cancer.



People diagnosed with cancer face a whole range of concerns about finances, medical worries, and emotional issues.

For example, you may feel that you are “complaining” if you express sadness at losing your hair because of treatment. You may think you should “just be glad to be alive” and that worrying about a “little thing” like hair loss shouldn’t concern



you. Or, if you’re a caregiver having a particularly difficult day, you may feel like you don’t have “the right” to be upset because of what your partner is experiencing. But it is not wrong to be as concerned about psychosocial effects as your physical state. In fact, in October 2007, the National Institute of Medicine (IOM)

released a report called “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs.” In the report, the IOM recommends that the standard of care for all cancer patients must include addressing the emotional and practical effects of cancer.

The report names CancerCare® as one of the leaders in providing such psychosocial services. That’s because at CancerCare, we 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

At CancerCare, we often use the word “coping” to describe how people deal with their cancer situation. People sometimes mistakenly think that coping means just living with a problem,

Coping Is...

- Managing and understanding what you need to live with your problems
- Making efforts to bring your problems under control
- Maintaining a healthy balance of realism and cautious optimism

Coping Is Not...

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

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.

Learning About Medicine

One of the biggest challenges for people with cancer is learning all the complex medical aspects of the disease. 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. The "wrong" choice, they worry, could make their condition worse.

One of the reasons why making choices is often overwhelming and confusing is the vast amount of information available

on the Internet, some of it unreliable. Advertisements on television and health stories in newspapers and magazines add to this outpouring of information. It's difficult to sift through everything. Throw into that mix the different doctors involved in your care, along with well-meaning friends and family

offering opinions, and it all adds up to what people with cancer describe as “too many voices.”

People with cancer know they are expected to take part in care and treatment decisions. Because treatment

nowadays often takes place in an **outpatient** setting, it allows for greater freedom. But 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:

- **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 doctor’s visit, bring these questions with you so you can keep track of what you need to know.
- **During your doctor’s visits, take notes** or ask a family



Can I Trust This Website?

Questions You Should Ask

What is the purpose of the website—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.

What is the source of the information? Generally, nationally known cancer centers, medical schools, large non-profit organizations, and government agencies provide the highest quality information.

Are you able to find contact information for the people behind the website? If you can't communicate with them, find another source.

Are the links relevant and appropriate for the site? Websites that refer you to unreliable or frankly commercial sources of information should be rejected.

Remember: The Internet is not a substitute for individual medical care. Use credible information you find on these sites to help you communicate more effectively with your doctor. For a list of trusted websites, see our resource guide on page 19.

member to take notes. Also ask your doctor if 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 to recommend books, brochures, and websites.** For tips on evaluating websites, see the box above.
- **Find trustworthy educational programs** about your cancer. CancerCare® offers more than 50 free Telephone Education Workshops every year that provide people with reliable information from experts on a range of cancer diagnoses and topics.

Finding Financial Help

Cancer is an expensive illness. Half of the people who contact CancerCare® each year cite financial need as a major source of difficulty. Some have no health insurance, some are insured but don't have coverage for parts of their treatment such as



prescription drugs, and many do not have extra 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 means their income goes down at the same time their bills pile up.

Financial stress often causes emotional stress. When a family is under new financial pressures, it can create feelings of resentment and sadness. 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 different forms, government and non-profit programs, and other sources of financial relief.

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 medical 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.** You can order a free fact sheet from CancerCare called “Getting to Know Your Entitlements” that outlines all the different sources of help available.
- **Learn how private organizations can help you.** Many pharmaceutical companies have programs to help low-income patients pay for prescription drugs. See our resource guide on page 19.
- **Talk directly to your creditors** if you expect to—or have already—run out of money and cannot meet your daily living expenses. Many utility and mortgage companies will work out a payment plan with you *before* a crisis develops.

Dealing With the Emotional Impact

The words “you have cancer” are 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, 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 75. Younger people may feel more confusion about having cancer at an age when they usually

feel invincible, and none of their friends is ill. On the other hand, an older person may have fewer family members to rely



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, the Book of Psalms, 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.
- **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.
- **Retreat to spiritual spaces,** natural settings, or concerts and museums to cultivate a spiritual sense of peace.
- **Keep a journal** to express your feelings, thoughts, and memories. It can contribute to your process of self-discovery and spiritual development.

A diagnosis of cancer can start a process of looking inward for a stronger connection to what is most meaningful and sacred. Out of the turmoil of this crisis, you may find strength and deeper meaning in your life.

on; perhaps children have moved away and started their own families, or there is no spouse at home who can care for his or her 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 your needs now.

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 expressions.

■ **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 or “buddy” program.**

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 run support groups on 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 a medicine for anxiety or depression.



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: the fact that you are the expert on your own life. You *can* manage many aspects of cancer that will help you cope better with the disease. CancerCare, and the organizations listed on page 19, are here to give you help and support as you travel this difficult terrain.

Frequently Asked Questions

Q **Should I be considering a clinical trial? It makes me nervous to think scientists will be “experimenting” on me.**

A A clinical trial is a research study that tests a new treatment. There are clinical trials to study not only cancer treatments, but side effect management, how people fare after treatment, and even cancer prevention. However, it is important to remember that, in most cases, *the new treatment being tested has already shown promise of being an improvement over the current treatment.* It is not just an unregulated experiment. In fact, many clinical trials are tests to see how much *better* a new treatment works than the current one. People in clinical trials are among the first to receive new treatments and are closely monitored by physicians and other researchers involved in the trial.

There are medical, practical, and emotional questions you should consider when deciding whether or not to join a clinical trial. But it’s always a good idea to talk to your doctor about clinical trials to see whether they may be right for you.

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 CancerCare for Kids® program helps parents and children cope with the effect 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 well managed with the help of your doctor and anti-nausea medications. Also, there are some things you can do on your own to bring relief:

- Distract yourself with music, television, or other activities you enjoy.
- Wear loose-fitting clothing that doesn't bind or add stress to your body.
- Rinse your mouth often to eliminate any bad taste.
- Avoid strong food odors, which can bring on nausea.
- Explore how your taste buds may have changed. Determine what foods taste good to you now.

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.

If you are not able to set up a system like this, you can also get **home care** assistance through your hospital, non-profit agencies, and private organizations. Many times, home care costs are covered by insurance, if part of the care involves administering medical treatment. See page 19 for a list of resources.

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 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 on page 19.

Q My husband was just diagnosed with advanced 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 legal 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. It is an honorable and acceptable decision. End-of-life care can also give the person with cancer and family members the opportunity to reconcile some of their memories, sadness, and complex emotions in this final time together. For a list of end-of-life resources, see page 20.

Glossary

case manager Specialists who work for insurance and other types of agencies. Case managers are responsible for helping clients gain access to the resources and services they need by cutting through red tape and acting as advocates.

clinical trials Research studies that test new treatments in patients, under carefully controlled conditions. Clinical trials are the gold standard by which doctors and scientists measure the worth of new therapies.

diagnosis The identification of a disease from its signs and symptoms.

entitlements Government programs that guarantee and provide benefits to a particular group.

home care Assistance that provides both medical and daily care for people who are homebound. Examples of home care are administering medications at home; monitoring bodily functions; as well as basic home functions of cooking, cleaning, and providing personal assistance to a patient.

oncology social workers Professionals who have specialized training in how a diagnosis of cancer affects a person and his or her family and friends. Oncology social workers have Master's degrees and are trained to help cancer patients and their families overcome the problems that accompany the disease, such as economic need, physical disability, social adjustment, and psychological care.

outpatient An outpatient is someone who is not hospitalized overnight but who visits a hospital, clinic, or associated facility for diagnosis or treatment.

palliative care Relieving or soothing the symptoms of a disease without aiming for a cure.

prognosis The act of foretelling the course of a disease. Also refers to the prospect of survival and recovery from a disease.

psychiatrist A medical doctor (MD) who specializes in the diagnosis and treatment of mental disorders. Psychiatrists offer counseling, also known as “talk therapy,” and may prescribe medications that help people overcome anxiety and depression.

psychologist A mental health professional with a doctoral degree (PhD) in psychology, which is the study of the mind and behavior. Psychologists offer talk therapy but cannot prescribe medications that deal with anxiety or depression, for instance.

psychosocial aspects The parts of life, other than a patient’s physical well-being, that are affected by cancer, including self-image, work, family, and approach to living.

support groups Sometimes led by professionals such as social workers, these groups enable those who join them to voice concerns openly, exchange information, and help each other cope with challenges they are facing.

Resources

We at CancerCare® know that this list includes only a few of the organizations available to help you. Call our trained social work staff to find resources that can help with your particular situation: 1-800-813-HOPE (4673).

■ FOR MEDICAL INFORMATION ABOUT CANCER AND ITS TREATMENTS

American Cancer Society

1-800-227-2345

www.cancer.org

Cancer.Net

(patient website of the American Society of Clinical Oncology)

1-888-651-3038

www.cancer.net

National Cancer Institute

Cancer Information Service

Support line: 1-800-422-6237

www.cancer.gov

National Comprehensive Cancer Network

Treatment Guidelines for Patients

1-888-909-6226

www.nccn.org

■ FOR FINANCIAL GUIDANCE AND ASSISTANCE

CancerCare

1-800-813-HOPE (4673)

www.cancercare.org

Partnership for Prescription Assistance

1-888-477-2669

www.pparx.org

Social Security Administration

1-800-772-1213

www.ssa.gov

■ FOR COUNSELING AND SUPPORT GROUPS

CancerCare

1-800-813-HOPE (4673)

www.cancercare.org

Cancer Hope Network (one-to-one “buddy” program)

1-877-467-3638

www.cancerhopenetwork.org

The Wellness Community

1-888-793-9355

www.thewellnesscommunity.org

■ **FOR CLINICAL TRIALS INFORMATION**

Coalition of Cancer Cooperative Groups

1-877-520-4457

www.CancerTrialsHelp.org

National Cancer Institute

1-800-422-6237

www.cancer.gov/clinicaltrials

■ **FOR HOME CARE RESOURCES**

National Association for Home Care and Hospice

202-547-7424

www.nahc.org

U.S. Administration on Aging

1-800-677-1116

www.eldercare.gov

■ **FOR EMPLOYMENT AND LEGAL RIGHTS**

CancerCare

1-800-813-HOPE (4673)

www.cancercare.org

National Partnership for Women & Families

202-986-2600

www.nationalpartnership.org

Patient Advocate Foundation

1-800-532-5274

www.patientadvocate.org

■ **FOR END-OF-LIFE CARE**

CancerCare

1-800-813-HOPE (4673)

www.cancercare.org

Hospice Foundation of America

1-800-854-3402

www.hospicefoundation.org

National Hospice and Palliative Care Organization

1-800-658-8898

www.nhpco.org



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The information presented in this patient booklet is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

All people depicted in the photographs in this booklet are models and are used for illustrative purposes only.

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When one word changes your world,

CANCERcare[®]

makes all the difference



With CancerCare,
the difference comes from:

- Professional oncology social workers
- Free counseling for you and your loved ones
- Education and practical help
- Up-to-date information

Our trusted team of professionally trained oncology social workers provides free counseling, education and practical help for you and your loved ones.



CANCERcare[®]

Help and Hope

1-800-813-HOPE (4673)

www.cancer.org