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After Treatment Ends: Tools for the Adult Cancer Survivor

Presented by

Rosalie Canosa, LCSW-R
CancerCare

Learn about:

- Long-term side effects
- Emotional concerns
- Financial issues
- Coping tips and resources



CANCERcare[®]

Help and Hope



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 and support groups, education, financial assistance, and practical help—are provided by professional oncology social workers and are completely free of charge. Founded in 1944, CancerCare provided individual help to more than 100,000 people last year, in addition to serving more than 1 million unique visitors to our websites. For more information, call 1-800-813-HOPE (4673) or visit www.cancercares.org.

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This booklet was made possible by an educational grant
from Genentech BioOncology.

Today, more people are living with and beyond cancer.

Nearly one in two men and one in three women will develop some form of cancer during their lifetime. Each year in the United States alone, 1.4 million people are diagnosed with cancer. The good news is that more people are living with and beyond cancer.

In the 1970s, less than 50 percent of people with cancer lived five years or more after their diagnosis. Now, nearly 70 percent of people with cancer live five years or more. The number of post-treatment cancer survivors in the United States (those who have finished their prescribed cancer treatments) has grown to about 12 million.

This booklet aims to help people who were diagnosed with cancer in their adult years and who have finished treatment. In these pages you will learn about:

- How to manage the short- and long-term physical effects of your cancer and treatment
- Sources of support for emotional and spiritual concerns
- Tips for managing your finances
- Answers to common questions about life after treatment
- Resources that can improve the quality of your life and health

Medical Issues After Treatment Ends

Researchers and health care providers now have a better understanding of cancer and how to treat it. But they are only beginning to study the long-term effect cancer has on all aspects of a person's life after treatment ends.

For instance, doctors now know that nearly three-quarters of all cancer survivors experience some type of physical symptoms resulting from medical treatments they received for their cancer. Some side effects you had during treatment can continue afterward, while other side effects may show up months or even years later.

And although some side effects can be temporary, others may be longer lasting, serious, or even life-threatening. It's important to let your health care team know about any symptoms you experience so they can help you manage them.

These are some common side effects resulting from cancer treatment:

Fatigue You may notice that you become tired more quickly when doing routine tasks or lack the energy for activities you used to enjoy.

Memory and thinking problems Often called "chemobrain," this side effect of chemotherapy causes some people to have trouble remembering simple things.

Changes in your diet The way in which certain foods taste, the foods your body will tolerate, and your ability to taste or enjoy food may be affected.



Bone or joint pain It's important to maintain your bone health with medications your doctor may prescribe and/or a proper diet.

Changes in appearance Hair loss or scars from cancer surgery can affect a survivor's quality of life.

Neuropathy Some chemotherapies can cause numbness, tingling, or pain in the hands or feet.

Lymphedema When lymph nodes are removed during cancer surgery, swelling in the arms, legs, neck, or face may occur because of fluids that build up in those areas.

Changes in intimacy and sexuality Both women and men can experience changes in fertility (ability to have a baby), sexual functioning, or how they feel about their body or appearance, which can affect intimacy.

Lingering side effects can be frustrating, especially when you expect to feel better when treatment is over. Keep in mind, though, that many side effects gradually lessen with time as your body heals and recovers from treatment. However, people experience these changes at different rates and in individual ways.



It can be very useful to keep a daily log of any side effects you experience. Note the date and time the symptoms occur and rate them on a scale of 1 to 10 to measure how strongly they affect you. These notes will make it easier to share details of your symptoms with your doctor.

Many cancer treatments put you at an increased risk of developing serious long-term health conditions that must be watched or managed throughout your life. Some of these conditions may include:

- Osteoporosis, a condition in which bones thin and become brittle
- An increased risk of stroke
- Diabetes
- Premature aging
- Reduced functioning of organs affected by treatment

Because of the many side effects and other health conditions that can occur, finishing cancer treatment gives way to a new period of follow-up care. During this time, your health care team continues to monitor you. This is often referred to, in medical terms, as “surveillance.” Your doctors check for side effects such as those discussed above. They also look for symptoms of recurrence (the return of a cancer), cancer spreading to other parts of the body, or new cancers developing.

THE SURVIVORSHIP CARE PLAN

One helpful tool for managing your follow-up care is a survivorship care plan. This document includes a summary of your diagnosis and all the treatments you received, as well as a follow-up plan of the steps you need to take to achieve the best health and well-being possible.

The survivorship care plan is a very important part of follow-up care for everyone who completes treatment for cancer. It helps you work effectively with your primary care doctor as well as other members of your health care team. You can use the checklist on the next page as a guide.

Survivorship Care Plan Checklist

Use this list as a guide when creating your personalized survivorship care plan. Ask your doctor for a **treatment summary**, which should include:

- The type and stage of the cancer(s) you were diagnosed with, as well as the date you were diagnosed
- The types of treatment you received (including surgical procedures, names of chemotherapy drugs, radiation doses, and all tests that were performed) and dates received
- Complications experienced (such as side effects, transfusions, and hospitalizations)
- Other treatments used (such as physical therapy, acupuncture, herbs, vitamins, or other alternative treatments)

Discuss with your doctor what your **follow-up plan** will be. This should include:

- A description of your state of health at the end of treatment
- A future schedule of visits (time and date)
- Who will deliver follow-up care (and where)
- Tests that will be done and why they are needed (such as those watching for a recurrence)
- What long-term effects might occur (such as swelling or numbness in the limbs, pain, or depression), how to watch for them, and how they will be treated
- Symptoms to watch for that might signal a return of your cancer
- A list of any habits you may have that can interfere with your recovery, and the steps you will take to adopt a more healthy lifestyle

Common Emotions Faced by Survivors

With the end of treatment often comes a sense of relief, accomplishment, and even joy in having gotten through a difficult experience. Yet for many cancer survivors, it is also a stressful time filled with new routines to learn, as well as mixed feelings about what they've just gone through. Many people find themselves unsure of how to move forward, wondering, "Now what?"

As a patient, you may have been so busy learning about your diagnosis, working with your medical team, and going through treatment that you didn't fully feel the emotional impact of your diagnosis until after you finished treatment. The fact is, the side effects of cancer and its treatment are more than physical. They are also emotional. It's common for many cancer survivors to have a variety of complex and often conflicting feelings about their diagnosis, treatment, and recovery.

For example, it is normal to feel relieved that treatment is over, yet angry or sad about having gone through such a serious illness. Or, you may feel guilty about surviving a diagnosis that other people do not. You may also feel anxious and fearful about the cancer coming back, or worried that the treatment didn't work. It is normal, too, to feel confused about what you've been through and to be concerned about the future.

Family and friends can provide much comfort and support during this time. However, survivors often feel a bit isolated



Emotional Support for Cancer Survivors

To cope with difficult emotions, the following types of help are available:

- **Individual counseling** provides people a chance to examine and better manage the many complex feelings that arise from surviving cancer.
- **Support groups** include peer-to-peer counseling, as well as counseling led by professional therapists or social workers.
- **Survivor matching programs** connect people facing similar diagnoses or situations.

from loved ones and the world around them. Loved ones usually mean well, but they might not be fully aware of all the emotional challenges that can arise for you after treatment is over. Sometimes, these emotions can be overwhelming, interfering with your day-to-day activities and even your health.

It is important to be able to talk openly with your health care team about any emotional symptoms you are experiencing as a result of your cancer. Members of your team can provide tips for coping or refer you to other sources of support. CancerCare®, for example, provides free counseling from professional oncology social workers. Other resources are listed on pages 19 and 20 of this booklet.

THE 'NEW NORMAL'

Another concern faced by many cancer survivors is the realization that life after their diagnosis and treatment never really goes back to what it was before cancer. Many survivors find they are not able to return to their old “normal” life but must adapt to a “new normal.”

Understanding what your new normal is can take time. This process may involve:

- Reflecting on what you've been through.
- Identifying changes you might want to make in your life.
- Recognizing what you've learned and what's changed about yourself.
- Re-evaluating personal relationships or professional goals.
- Discovering new ways of finding meaning and fulfillment.

As part of this process, you may find it helpful to seek out the support of others who understand what you're going through. Joining a support group for post-treatment survivors, such as those offered by *CancerCare*, can allow you to share with and learn from others who are facing similar issues, such as fear of recurrence, living with uncertainty, lingering side effects, and going back to work.

Spirituality and Survivorship

Spirituality means different things to different people. For some, spirituality is linked to a religious faith. Many survivors report that their faith is part of what got them through the cancer experience and that afterward it continues to give them strength in the face of often difficult circumstances. For other people, spirituality is about the personal beliefs that bring comfort, meaning, and purpose to their lives.

However you define spirituality, recent studies show that it can play an important role in coping with the recovery and



Some Ways to Find Comfort and Meaning

- Read uplifting stories about the human spirit.
- Pray or meditate to help you gain perspective.
- Take part in community or social gatherings for your own support and to support others.
- Talk with others who have had similar experiences.
- Find resources at a place of worship for people living with serious illnesses like cancer.
- Be kind to yourself. Allow for your full range of feelings to come out. These feelings might include doubt, fear, anger, and questioning one's faith. Such feelings are normal.

healing process from cancer treatment and its aftereffects.

Spirituality can be expressed in many ways: in a traditional house of worship, out in nature, or through involvement in the arts or community events, for example. And there are many activities that can help you nurture your spiritual side, such as prayer, meditation, and reflection.

It is not uncommon for people diagnosed with cancer to question why the illness happened to them and to search for meaning in the experience. Reading spiritual texts, writing in a journal, or even blogging about your experiences can be ways to explore your questions and beliefs about meaning and faith. If you do not feel the need to seek answers or find special meaning in your experience, that is okay too.

Like any serious illness, cancer can also challenge the foundations of a survivor's religious faith or spirituality. If that is the case for you, you may find it helpful to speak about your feelings with a clergy person of your faith. Or you may wish to talk with someone at an interfaith center

if you would rather speak with someone outside your own tradition. Many faiths also have written materials available on how to cope with a spiritual crisis.

Returning to Work: Laws You Should Know

Many cancer survivors are able to continue working through and beyond their treatment. They may miss only a few days of work or require just a temporary reduction in their work schedules. Others may have to stop working during treatment and return later. Whether you continue to work may depend on your workplace; each company has its own unique culture.

Many organizations are supportive of employees during and after treatment. For example, some employers proactively let their employees know what arrangements they can make should a cancer survivor want to continue working. However, sometimes employers and coworkers may assume that a cancer survivor is unable to perform job responsibilities as well as he or she did before the cancer diagnosis. Employers may regard making any special arrangements as a hardship on the business. It is important to know the laws that protect you in the workplace, including:

The Americans with Disability Act (ADA) prohibits discrimination against people with disabilities. Organizations with 15 or more employees must follow ADA guidelines. To qualify for ADA protection, you must:

- Meet the ADA definition of a “disabled person”
- Qualify for the job and be able to perform its essential functions
- Not pose a risk to your own or others’ health and safety
- Not cause “undue hardship” to your employer for any accommodations you might need

People living with and beyond cancer often need flexible work hours in order to go to medical appointments. Sometimes, restructuring a job or reducing the number of hours you work may be considered reasonable, especially if you work through treatment or plan to return to the workplace after treatment ends.

If you require flextime, it is important to tell your supervisor or your human resources department about your cancer history in order to be protected under the ADA. If you don't give any reason for frequent flextime requests, you could risk losing your job. For more information, call 1-800-514-0301 or visit the ADA website, www.ada.gov.

The Family and Medical Leave Act (FMLA)

enables people dealing with a serious illness, or one of their family members, to take unpaid leave for up to 12 weeks within one calendar year. The FMLA applies to organizations with 50 or more employees.



The employee must have worked with his or her employer for at least one year, and employers must continue providing health benefits during the leave. Leave does not have to be taken all at once but can be taken in blocks of time. To learn more, visit the U.S. Department of Labor's website at www.dol.gov and search for FMLA.

If you feel you are being treated unfairly, contact the **Equal Employment Opportunity Commission (EEOC)**. The EEOC is a federal agency that enforces the provisions of the ADA and FMLA and helps people who feel they have been

discriminated against in the workplace. Call 1-800-669-4000 or visit www.eeoc.gov.

Financial Help When You Are Unable to Work

Some cancer survivors who have been employed choose to retire. Others may not be able to return to work as a result of complications from their illness. If you are unable to work after your treatment ends, there is help.

Some options for cancer survivors in need of health insurance include:

Medicare and Medicaid Medicare is a government-provided health care plan for people 65 and older and those who are disabled (cancer may qualify as a disability). Medicaid provides health care services for people under a certain income level. Contact the Centers for Medicare and Medicaid Services at 1-877-267-2323 or visit www.cms.hhs.gov to find out whether you are eligible for these programs.

COBRA If you have left a job recently and were covered by an employer's health insurance, you may be able to continue your coverage under COBRA (the Consolidated Omnibus Budget Reconciliation Act). This law requires employers to make available health insurance coverage through their plan to former employees for up to 18 months after employment has ended. Beneficiaries are required to pay for COBRA coverage. Visit the U.S. Department of Labor website, www.dol.gov, to learn if you are eligible. Find out, too, whether your state offers basic unemployment health insurance coverage.

For sources of income, find out if you are eligible for Social Security Disability Insurance or Supplemental Security Income by calling 1-800-772-1213 or visiting the Social Security website, www.socialsecurity.gov/disability/. Life insurance policies and retirement plans can also be sources of cash.

Should you be laid off from your job, immediately apply for unemployment insurance through your state employment board. The amount of benefits varies from state to state, and benefits are provided only for a short period (usually 26 weeks). Most states require some sort of proof that you are seeking employment while drawing unemployment benefits.

Tips for Managing Medical Debt

Whether or not you are insured, you may find yourself struggling with outstanding medical bills from your cancer treatment. Consider the following options.

If you are insured:

- **Read your insurance policy and understand the terms of your contract.** If you have questions, ask your insurance company, insurance broker, or the human resources staff at your place of employment to explain it to you. Your insurer may have denied a claim even though you are entitled to coverage. The Kaiser Family Foundation has an excellent guide on how to dispute claims with your insurer. For more information, visit www.kff.org/insurance/consumer.cfm.
- **Ask the hospital or doctor to consider the insurance payment as “payment in full.”** Many people don’t think to do this, and it is often more successful than expected. Some hospitals have funds to offset medical services that aren’t fully covered by insurance.

Whether or not you have insurance:

- **Double check all bills and EOBs (explanation of benefits).** You’d be surprised how often billing mistakes are made. If you don’t receive an itemized bill, ask for one. Look for incorrect dates of service (for instance, you shouldn’t be billed for the room on the day you were

discharged) and fees billed more than once for the same test or procedure.

- **Negotiate the outstanding balance by asking for a discount.** According to a Wall Street Journal survey, 70 percent of adults who talked with a hospital said they were successful in negotiating a lower price for their medical bills; 61 percent were successful with their doctor. You will likely get a greater discount (sometimes as high as 50 percent) if you pay the outstanding balance in a lump sum.
- **Work out a payment plan.** Often, doctors and hospitals are willing to negotiate interest-free monthly payments.
- **Seek out help from nonprofit organizations** such as the Patient Advocate Foundation (1-800-532-5274 or www.patientadvocate.org) and CancerCare®.

CancerCare Can Help

Cancer is a major event in anyone's life. Although no two cancer survivors will face the exact same circumstances or concerns after treatment, many survivors have similar questions, such as "Will I recover?" "What happens next?" "Will the cancer come back?" and "What is normal now?"

This booklet has described some of the resources that exist for post-treatment survivors. You can find more help and support by talking directly to a CancerCare professional oncology social worker. We can help you find resources in your community. We also provide free counseling, support groups, education, and financial assistance.

To learn more about how CancerCare helps, call **1-800-813-HOPE (4673)** or visit **www.cancercare.org**.

Frequently Asked Questions

Q It has been a year since I finished treatment, and I am trying to take things day by day. But I worry about my family and taking care of their future. What should I be doing to make sure they'll be okay?

A Providing for your family's future security can be included in your Cancer Survivorship Plan (see page 6). It's important to have a financial plan, one that details your assets, savings, retirement accounts, investments, and any expected income from these sources. The Lance Armstrong Foundation (1-866-673-7205 or www.laf.org) offers worksheets that can help you organize all of this information and make it easily accessible.

A financial plan also details your expenses, including all the costs associated with your treatment. Your plan should state future goals for how to cover your expenses and list alternative sources of income if you are unemployed, on disability, or earning less income after treatment ends. Seek out a professional financial planner, who can help you create a plan based on your individual circumstances. The American Cancer Society offers several helpful booklets on financial concerns for cancer survivors and their families, including *How to Find a Financial Planner Sensitive to Cancer Issues*. You can download the booklets from www.cancer.org or order them by calling 1-800-227-2345. (For more practical tips on finances, see the next question and answer below.)

You also want to make sure that you have other important documents in order, including power of attorney, a living will, and a regular will. With "advance directives," you put into writing your wishes. Be open with your loved ones about your concerns, your present abilities, and any changes in your physical or emotional state since ending treatment

and how these changes might affect them. Fostering open communication with your loved ones will help them feel more secure about your future and theirs and will allow them to share any concerns or questions they might have. Also, recognize that professional support might be helpful to them, as a cancer diagnosis affects the entire family.

Q The financial impact of treating my cancer has hit me and my family hard. The bills just keep coming, and I am having trouble keeping on top of them all. How can I manage them?

A Cancer is a very expensive illness. Even with insurance, most people are financially unprepared for the out-of-pocket expenses for their medical care. Covering general daily living expenses can also be challenging, especially when your treatment and follow-up care have prevented you from earning a regular income.

Getting organized can give you a greater sense of control over your life and priorities, including financial matters. Here are a few simple tips from Cancer.Net (www.cancer.net) for organizing your bills and other paperwork:

- Keep all cancer and treatment information in one place, in a filing system that works for you and makes it easy to find information. Keep bills and important papers in clearly labeled folders, and file new information as soon as possible, so it doesn't get lost.
- If you have health insurance, ask your insurance provider to assign you to a case manager, so you can talk with the same person each time you need to call. Take written notes of any conversations with insurance company representatives, including the date, name of the person you spoke with, and what was said.
- Determine which bills demand payment, which can be deferred, and which ones you can arrange a payment plan

for. Negotiate payment plans for your monthly bills with your utility company, phone provider, and other creditors who may offer assistance programs to people in need.

Read Cancer.Net's guide "Managing the Cost of Cancer" for more tips. For additional guidance in managing medical debt, call the Patient Advocate Foundation (1-800-532-5274) to speak with a trained case manager or visit their website, www.patientadvocate.org.

Q I am finished with treatment and currently cancer-free. Yet I am fearful that the cancer will come back. What can I do to lessen my anxiety?

A Fear of recurrence is not at all uncommon for cancer survivors, and you are not alone. It's important to address your concerns, because over time, ongoing anxiety can often lead to fatigue and depression. Take control of those things you can influence. Here are a few practical suggestions to help you better manage anxiety:

- **Engage in activities such as yoga and relaxation techniques:** deep breathing exercises, meditation, and guided imagery are a few examples.
- **Seek out support.** Speaking with others in a support group can help relieve anxiety and provide you with new ways of coping.
- **Express your feelings to a counselor** one on one in a nurturing environment. The process of openly exploring emotions helps many people feel less anxious.
- **Make healthier choices.** These choices may include increasing physical activity and adjusting your diet.
- **Stay actively involved in your follow-up care** by asking your doctor specific questions about the likelihood of recurrence. Discuss what you can do to minimize your chances of recurrence.

Resources

MEDICAL INFORMATION FOR SURVIVORS

- **American Cancer Society**
1-800-227-2345
www.cancer.org
- **Cancer.Net**
Survivorship information from the American Society of Clinical Oncology
www.cancer.net/patient/survivorship
- **National Cancer Institute**
Office of Cancer Survivorship
<http://dccps.nci.nih.gov/ocs>

COUNSELING AND SUPPORT GROUPS

- **CancerCare**
1-800-813-HOPE (4673)
www.cancercare.org
- **Cancer Support Community**
A merger of Gilda's Club and The Wellness Community
www.cancersupportcommunity.org

INSURANCE AND LEGAL CONCERNS

- **Medicare and Medicaid**
1-877-267-2323
www.cms.hhs.gov
- **Americans with Disability Act (ADA)**
1-800-514-0301
www.ada.gov
- **Cancer and Careers**
www.cancerandcareers.org
- **Consumer Guides to Getting and Keeping Health Insurance**
www.healthinsuranceinfo.net
- **Equal Employment Opportunity Commission (EEOC)**
1-800-669-4000
www.eeoc.gov

INSURANCE AND LEGAL CONCERNS *continued*

- **Kaiser Family Foundation**
www.kff.org/insurance/consumer.cfm
- **LawHelp.org**
www.lawhelp.org
- **Patient Advocate Foundation**
1-800-532-5274
www.patientadvocate.org
- **U.S. Department of Labor**
www.dol.gov

SURVIVORSHIP SUPPORT

- **Lance Armstrong Foundation**
1-866-673-7205
www.laf.org
- **National Coalition for Cancer Survivorship (NCCS)**
www.canceradvocacy.org

FERTILITY CONCERNS

- **Fertile Hope**
1-866-965-7205
www.fertilehope.org

FINANCIAL ASSISTANCE

- **CancerCare**
1-800-813-HOPE (4673)
www.cancercares.org
- **Cancer Financial Assistance Coalition**
www.cancerfac.org
- **Partnership for Prescription Assistance**
1-888-477-2669
www.pparx.org
- **U.S. Social Security Administration**
For information on Social Security Disability Insurance or Supplemental Security Income
1-800-772-1213
www.socialsecurity.gov/disability/



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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.



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Help and Hope

1-800-813-HOPE (4673)

www.cancercare.org