

AFTER TREATMENT ENDS:
Tools for the Adult
Cancer Survivor

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Today, more people are living with and beyond cancer than ever before. The number of post-treatment cancer survivors in the United States (those who have finished their prescribed cancer treatments) continues to grow.

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-term and long-term physical effects of cancer and its 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 your quality of life and health

Medical Concerns After Treatment Ends

Today, researchers and health care providers have a better understanding of cancer and post-treatment survivorship. For instance, doctors now know that many cancer survivors experience some type of physical symptoms resulting from medical treatments they received for their cancer.

Some side effects experienced 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.

Common side effects resulting from cancer treatment can include:

- **Fatigue.** You may notice becoming tired more quickly when doing routine tasks or lacking 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 concentrating or remembering things.
- **Changes in diet and digestion.** The way in which certain foods taste, the foods your body will tolerate, and your ability to taste or enjoy food may be affected.
- **Dental problems.** Some cancer treatments can cause symptoms like dry mouth or increase the risk of developing long-term dental issues like gum disease.

- **Bone or joint pain.** Some people may develop bone thinning (osteoporosis) or joint pain as a result of their treatments, so it's important to maintain 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 how you feel about your body and your perception of how others see you.
- **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 children), 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 now that 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. Even consider recording other details including the activity you're engaged in when you first notice the symptom and whether any relief measures you try are effective. These notes will make it easier to share details of your symptoms with your doctor and may guide your doctor in finding more effective strategies to help you manage your symptoms in the future. See Daily Symptom Log on page 25 of this booklet.

Because of 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 previously discussed. 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 below 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 you may have experienced (such as side effects, transfusions, and hospitalizations)
- Other treatments used (such as physical therapy, acupuncture, herbs, vitamins, or other alternative treatments)

Survivorship Care Plan Checklist Continued...

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 haven't fully experienced the emotional impact of your diagnosis until now that you have 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 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 isolated 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 provides free counseling from professional oncology social workers. Other resources are listed on pages 26 and 27 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.



Emotional Support for Cancer Survivors

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

- **Counseling.** Feeling stressed or anxious while coping with cancer is common. Face-to-face or telephone counseling provides a safe space to voice any concerns to better cope with these changes.
- **Support groups.** Building a support network can lessen the isolation that often comes with a cancer diagnosis. A support group is a unique opportunity to connect with others impacted by cancer. CancerCare provides support groups online, over the phone and face-to-face. We offer 120+ online support groups each year for specific cancer diagnoses, caregivers and the bereaved that are password-protected.

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. For other people, spirituality is about the personal beliefs that bring comfort, meaning, and purpose to their lives.

However you define spirituality, studies show that it can play an important role in coping with the recovery and healing process from cancer treatment and its after effects.

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.



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 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.

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 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 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.

Know the Laws that Protect You in the Workplace.

The Americans with Disabilities Act (ADA)

The 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)

FMLA enables people coping 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.

Equal Employment Opportunity Commission (EEOC)

If you feel you are being treated unfairly, contact the 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 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 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 health insurance coverage available 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.

Social Security

For sources of income, find out if you are eligible for Social Security Disability Insurance or Supplemental Security Income by calling 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, HealthCare.gov has an excellent guide on how to dispute claims with at www.healthcare.gov/appeal-insurance-company-decision/appeals/ or read CancerCare's fact sheet titled, "Understanding Your Insurance Coverage."

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.

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 (www.patientadvocate.org or 800-532-5274) and CancerCare. Call 800-813-HOPE (4673) and speak with a CancerCare professional oncology social worker who can help you explore your options and find appropriate resources.



CancerCare Can Help

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

You will likely also build your own personal support network, 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. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store; ask a friend who's a good listener to come over for a chat.

MORE ABOUT SURVIVORSHIP

Frequently Asked Questions

Q. I recently found out that I'm in remission but I am fearful that the cancer will come back. What can I do to lessen my anxiety?

A. Fear of recurrence (cancer returning) is very common and understandable in the context of your recent cancer experience. There are several ways in which you can manage this anxiety:

- **Practical.** Ask your oncologist about chances of recurrence and schedule regular tests to check for signs that the cancer may have returned and steps you can take to increase the chances that it will not. Assess your life and look at your daily routine. Are there things you could improve about your diet? Ways to increase your physical activity? Things you can do to help you relax? To sleep better?
- **Emotional.** Consider talking to a professional counselor, such as an oncology social worker at CancerCare who can suggest ways to manage your anxiety and help you process your feelings. Many cancer survivors also find support groups very helpful, as they can talk to other survivors with similar worries and fears and learn new coping skills. View support groups at CancerCare by visiting www.cancercare.org or read CancerCare's fact sheet titled, "The Value of an Oncology Social Worker" to learn more.
- **Social.** Talk to your trusted friends or family members about your concerns. Even if there are just one or two people with whom you feel comfortable sharing your fears, this can be a powerful way to get some relief from your anxiety. Making sure you continue to engage in hobbies and socialize with your friends is an essential and healthy form of distraction.

- **Spiritual.** Reflect on what makes your life meaningful, both before and after cancer. What values and activities are important to you? How can you continue to honor those things you hold dear? Focusing on the bigger picture can help minimize the anxiety and remind you what you can do in the here-and-now to live a full life.

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 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.

Survivorship Resources

MEDICAL INFORMATION FOR SURVIVORS

American Cancer Society

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
www.cancercontrol.cancer.gov/ocs/

SUPPORTIVE RESOURCES

CancerCare

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

Cancer Support Community

888-793-9355
www.cancersupportcommunity.org

LIVESTRONG Foundation

866-673-7205
www.livestrong.org

National Coalition for Cancer Survivorship (NCCS)

www.canceradvocacy.org

Survivorship Resources Continued

INSURANCE AND LEGAL CONCERNS

Medicare and Medicaid

877-267-2323
www.cms.gov

Americans with Disabilities Act (ADA)

800-514-0301
www.ada.gov

Cancer and Careers

www.cancerandcareers.org

Equal Employment Opportunity Commission (EEOC)

800-669-4000
www.eeoc.gov

Kaiser Family Foundation

www.kff.org/understanding-health-insurance/

LawHelp.org

www.lawhelp.org

Patient Advocate Foundation

800-532-5274
www.patientadvocate.org

U.S. Department of Labor

www.dol.gov

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