

AFTER TREATMENT ENDS:

Tools for the Post-Treatment Cancer Survivor

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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.

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

There are more than 17 million cancer survivors in the United States, and that number is expected to grow significantly in the coming years.

This booklet provides information for people who have completed initial treatment for cancer.



Medical Concerns After Treatment Ends

Many survivors experience physical symptoms resulting from treatments for their cancer. It's important to let your cancer care team know about any symptoms you experience so they can help you manage them.

Depending on the type of treatment you received, these side effects can include:

- **Fatigue.** You may tire more quickly when doing routine tasks, or lack the energy for activities you used to enjoy.
- **Memory and Cognitive problems.** Trouble concentrating or problems with memory may occur.
- **Food-related issues.** The way certain foods taste, the foods your body will tolerate and your ability to enjoy food may be affected.
- **Dental problems.** Some cancer treatments can increase the risk of having long-term dental issues, such as gum disease.
- **Bone or joint pain.** Some people may develop bone thinning (osteoporosis) or joint pain as a result of their treatments. It's important to maintain bone health with regular weight-bearing exercise (such as walking), a healthy diet and any medications your doctor may prescribe.
- **Neuropathy.** Some chemotherapies can cause numbness, tingling or pain in the hands or feet.
- **Lymphedema.** Swelling in the arms, legs, neck or face may occur when lymph nodes are removed during cancer surgery or radiation, because fluids can build up in those areas.

Other side effects that can occur include anxiety, depression, body image issues and sleep-related problems.

Problems with sexual function may also occur. During and after treatment, men and women may experience a decrease or loss of sexual desire or pain during sex. Women may experience vaginal dryness, numbness and difficulty in achieving orgasm. Men may experience the inability to achieve or maintain an erection and may have ejaculation problems. Let your health care team know about changes in your sexual health, as they may be able to recommend treatment options that can help.

It can take a while to recover after treatment is over. Some side effects may get better over time but not completely go away. Lingering side effects can be frustrating, especially when you expect to feel better now that treatment is over. It may be helpful to keep a daily log (on paper or in a digital format) of any side effects that you experience. The log should include:

- The specific side effect
- The time the side effect occurred
- The activity you were engaged in when the side effect occurred
- How strongly you were affected, on a scale of 1 to 10
- Any relief measure you might have taken and its effectiveness

This log will make it easier to share information with your health care team. Together, you can find ways to help manage these side effects.

Emotions After Treatment

With the end of treatment, there is often a sense of relief, accomplishment and even joy in having gotten through a difficult experience. However, it can also be a time of stress and conflicting emotions about your diagnosis, treatment and long-term recovery. These emotions can sometimes be overwhelming, interfering with your day-to-day activities and your health.

Family and friends can provide much comfort and support during this time, but they might not be fully aware of all the emotional challenges that can arise after your treatment is over. They may think that you now don't need the same level or type of support. Because of that, it is important that you talk openly with your health care team about any emotional symptoms you are experiencing as a result of your cancer. They can provide tips for coping or refer you to other sources of support.

As a post-treatment cancer survivor, you will likely need to adjust to your "new normal." Understanding what this means for you will likely take weeks, months or even years. This process may involve:

- Reflecting on what you've been through
- Realizing how your body has changed since your cancer
- Recognizing what you've learned about yourself
- Identifying changes that you might want to make in your life
- Re-evaluating personal relationships and/or professional goals
- Discovering new ways of finding meaning and fulfillment

As part of this process, you may find it helpful to seek the support

of others who understand what you're going through. Joining a support group for post-treatment survivors 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 (if you stopped working).

If you are finding that you feel anxious or depressed, speak to someone to get help.



Spirituality and Post-Treatment Survivorship

Spirituality means different things to different people. For some, spirituality is linked to a religious faith. For others, spirituality is about the personal beliefs that bring comfort, meaning and purpose to their lives. Spirituality can be expressed in a number of ways, including in a traditional house of worship, out in nature, or through involvement in the arts or community events. There are many activities that can help you nurture your spiritual side, such as prayer, meditation and reflection.

Studies show that spirituality—however you define it—can play an important role in coping with the recovery and healing process associated with cancer treatment. It is not uncommon to question why your illness happened 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 these questions.

Like any serious illness, cancer can challenge the foundations of a person'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 with someone at an interfaith center. Many faiths also have written materials on how to cope with a spiritual crisis.

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.



The Workplace

People living with and beyond cancer may have kept working during treatment, reduced their hours or stopped working altogether. You may have found co-workers to be helpful during treatment, but they may not realize you still might need help as you resume your activities. After treatment is over, you may need flexible work hours in order to go to medical appointments. In some instances, restructuring a job or reducing the number of hours you work may also be considered reasonable.

As a post-treatment survivor, it is important for you to be aware of the laws that protect you in the workplace.

The Americans with Disability 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”: a person who has a physical or mental impairment that substantially limits one or more major life activity
- 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

In order to be protected under the ADA, it is important to tell your supervisor or your human resources department about your cancer history. For more information, call 1-800-514-0301 or visit the ADA website at www.ada.gov.



The Family and Medical Leave Act (FMLA). The FMLA enables people dealing with a serious illness to take unpaid leave for up to 12 weeks within one calendar year. The FMLA applies to organizations with 50 or more employees. (The FMLA also applies to family members of people with serious illnesses.)

The employee must have worked with their employer for at least one year, and employers must continue to provide health benefits during the leave. The leave does not have to be taken all at once but can be taken in blocks of time (intermittently). 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). 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. For more information, or if you feel you are being treated unfairly, call 1-800-669-4000 or visit www.eeoc.gov.

Managing Medical Debt

Cancer is a very expensive illness. Even with health insurance, most people are financially unprepared for the out-of-pocket expenses associated with their medical care.

If you have health insurance, read your insurance policy carefully to understand the terms of your contract. If you have general questions or questions about a denied claim, contact your insurance company, insurance broker or the benefits representative at your place of employment. CancerCare’s fact sheet titled “Understanding Your Insurance Coverage” also provides valuable information.



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 call. Take notes on any conversations you have with insurance company representatives, including the date, name of the person you spoke with and what was said.
- **Determine which bills must be paid immediately**, which can be deferred and those for which you can arrange a payment plan. Negotiate payment plans for your non-medical monthly bills with your utility company, phone provider and other creditors who may offer assistance programs.

Additionally:

- **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.
- **Seek out help from nonprofit organizations** such as the Patient Advocate Foundation (800-532-5274 or www.patientadvocate.org), You can also contact CancerCare to speak with a professional oncology social worker who can help you explore your options and find appropriate resources.

- **Ask the hospital or doctor to consider any insurance payments 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.



CancerCare's Free Support Services and Programs

Even after treatment ends, it can be challenging to adjust to the necessary changes in your life caused by your cancer diagnosis.

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our master's-prepared oncology social workers can provide support and education, help in navigating the complicated health care system and offer 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, composed 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.



Frequently Asked Questions

Q: What is a survivorship care plan?

A: After your treatment ends, there will be a period of follow-up care during which your cancer care team will continue to monitor your health. The monitoring will be tailored the type of cancer you were treated for and other factors specific to your individual circumstances, and may include regularly-scheduled or intermittent medical tests.

A survivorship care plan is a very important part of your follow-up care. An effective written plan is developed in collaboration with your health care team and given to you and your primary care provider. It includes:

Treatment Summary:

- The type and stage of the cancer you had
- Date of diagnosis
- Treatments received, including dates started and stopped and dosages when appropriate
- Other treatments, such as physical therapy, acupuncture, herbs, vitamins or other alternative treatments
- Complications you may have had, including side effects and hospitalizations

Care Plan:

- A description of your state of health at the end of treatment
- A schedule of follow-up visits (time and date)
- Where and by whom follow-up care will be delivered
- Tests that will be done and why they are needed
- What long-term effects might occur and how to watch for them

- Symptoms to watch for that might signal that the cancer has come back
- A list of any habits you may have that can interfere with your recovery
- Steps you will take to adopt a healthier lifestyle

Additional information on creating a survivorship care plan can be found at <https://oncolife.oncolink.org>.

Q: Can you share guidance on communicating with my health care team?

A: Even though your primary cancer treatment has ended, it is important to remember that you are still a consumer of health care and will have ongoing communication with your oncologist and other members of your health care team.

Here are some tips for improving communication with your team:

Start (or continue) a health care journal. Having a health care journal or notebook (either on paper or in a digital format) will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. Keep a diary of your daily experiences, including any lingering side effects. You can separate your journal or notebook into different sections to help keep it organized.

Prepare a list of questions. Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, you should ask your most important questions first, and be as specific as possible.

Bring someone with you to your appointments. Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support when you go to your appointments. The person who accompanies you can serve as a second set of ears. They may also think of questions to ask your doctor or remember details about your post-treatment symptoms that you may have forgotten.

Write down your doctor's answers. Taking notes will help you remember your doctor's responses, advice and instructions. If you cannot write down the answers, ask the person who accompanies you to do that for you. If you have a mobile device, like a tablet or smartphone, ask if you can use it to take notes. Writing notes will help you review the information later.

Record your visit if your doctor allows it. Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends.

Incorporate other health care professionals into your team.

Your medical oncologist is an essential member of your health care team, but there are other health care professionals who can help you achieve and maintain the best possible health outcomes.

- Your local pharmacist is a great source of knowledge about the medications you are taking. Have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your oncologist knows of any other medical conditions you have, or any pain you are experiencing, so that they can consult with your primary care provider or your specialist if needed.
- Ask your oncologist to send a summary of your visits to your primary care provider and all providers involved in your care.

Q: I am unable to work. What are my options for health insurance?

A: If you are unable to work after your treatment ends, there is help. Options for post-treatment 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 whose income falls under a certain level. Contact the Centers for Medicare and Medicaid Services (CMS) at 877-267-2323 or visit www.cms.hhs.gov to find out whether you are eligible for either of 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.
- **Social Security.** Social Security Disability Insurance or Supplemental Security Income may be able to help with the cost of health insurance. For eligibility requirements, call 800-772-1213 or visit www.socialsecurity.gov/disability/.

On a related note: If you were laid off from your job, you should immediately apply for unemployment insurance through your state employment board. The length of benefits, benefit amount and eligibility requirements vary from state to state.



Resources

CancerCare®

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

American Cancer Society

800-227-2345
Survivorship: During and After Treatment
<https://www.cancer.org/treatment/survivorship-during-and-after-treatment.html/behealthyaftertreatment.html>

Cancer.Net

Survivorship information from the American Society of Clinical Oncology
www.cancer.net/patient/survivorship

National Cancer Institute

800-422-6237
www.cancer.gov

FINANCIAL AND OTHER ASSISTANCE

Cancer Financial Assistance Coalition

www.cancerfac.org

Patient Advocacy Foundation

<https://www.patientadvocate.org>

Medicine Assistance Tool

www.medicineassistancetool.org

Office of Cancer Survivorship

cancercontrol.cancer.gov/ocs/

National Coalition for Cancer Survivorship (NCCS)

www.canceradvocacy.org

Cancer Support Community

888-793-9355
www.cancersupportcommunity.org

LIVESTRONG Foundation

1-866-673-7205
www.livestrong.org

Oncolife Survivorship Care Plan

<https://oncolife.oncolink.org>

Cancer and Careers

www.cancerandcareers.org

Kaiser Family Foundation

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

This booklet is supported by Bristol Myers Squibb, an educational grant from Daiichi Sankyo, Inc., an independent educational grant from Merck & Co. Inc., Pharmacyclics LLC, an AbbVie Company and Janssen Biotech, Inc., administered by Janssen Scientific Affairs, LLC, and Takeda Oncology.



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