

# PATIENT RESOURCE

Fourth Edition

**FREE** take one

# CANCER SURVIVORSHIP

A GUIDE FOR PATIENTS AND THEIR FAMILIES

WHERE  
INFORMATION  
EQUALS HOPE

Published in partnership with



Global  
Resource for  
Advancing  
Cancer  
Education

  
CONTENT  
REVIEWED BY  
A DISTINGUISHED  
MEDICAL  
ADVISORY  
BOARD

PRP PATIENT RESOURCE PUBLISHING\*

# CANCER SURVIVORSHIP

Fourth Edition

## IN THIS GUIDE

- 1 Overview:** Survivorship transition brings challenges and opportunities
- 2 Survivorship Care Plan:** Creating a plan can help you define your goals moving forward
- 3 Survivor Story:** Helene Unger
- 4 Life After Cancer:** The road through survivorship leads to many changes and opportunities
- 6 Late Effects:** Be alert for side effects that may develop long after treatment ends
- 8 Emotional Late Effects:** Recognizing and managing your post-treatment emotions
- 9 Assistance:** Support and financial resources available for you

## PATIENT RESOURCE

Chief Executive Officer	<b>Mark A. Uhlig</b>
Co-Editor-in-Chief	<b>Charles M. Balch, MD, FACS</b>
Co-Editor-in-Chief	<b>Lillie D. Shockney, RN, BS, MAS, ONN-CG</b>
Senior Vice President	<b>Debby Easum</b>
Vice President, Operations	<b>Leann Sandifar</b>
Vice President, Publications	<b>Dana Campbell</b>
Managing Editor	<b>Colleen Scherer</b>
Staff Writer	<b>Marli Murphy</b>
Graphic Designer	<b>Michael St. George</b>
Medical Illustrator	<b>Todd Smith</b>
Circulation & Production Manager	<b>Sonia Wilson</b>
Vice Presidents, Business Development	<b>Amy Galey</b> <b>Kathy Hungerford</b>
National Account Executive	<b>Billy Dunbar</b>
Office Address	<b>8455 Lenexa Drive</b> <b>Overland Park, KS 66214</b>
For Additional Information	<b>prp@patientresource.com</b>
Advisory Board	<b>Visit our website at PatientResource.com to read bios of our Medical and Patient Advisory Board.</b>

**For Additional Copies:** To order additional copies of *Patient Resource Cancer Survivorship*, visit PatientResource.com, call 913-725-1600, or email orders@patientresource.com.

**Editorial Submissions:** Editorial submissions should be sent to editor@patientresource.com.

**Disclaimer:** Information presented in *Patient Resource Cancer Survivorship* is not intended as a substitute for the advice given by your health care provider. The opinions expressed in *Patient Resource Cancer Survivorship* are those of the authors and do not necessarily reflect the views of the publisher. Although *Patient Resource Cancer Survivorship* strives to present only accurate information, readers should not consider it as professional advice, which can only be given by a health care provider. Patient Resource, its authors, and its agents shall not be responsible or in any way liable for the continued currency of the information or for any errors, omissions or inaccuracies in this publication, whether arising from negligence or otherwise or for any consequences arising therefrom. Patient Resource, its authors, and its agents make no representations or warranties, whether express or implied, as to the accuracy, completeness or timeliness of the information contained herein or the results to be obtained from using the information. The publisher is not engaged in rendering medical or other professional services. The publication of advertisements, whether paid or not, and survivor stories is not an endorsement. If medical or other expert assistance is required, the services of a competent professional person should be sought.

© 2019 Patient Resource LLC. All rights reserved.  
PRP PATIENT RESOURCE PUBLISHING®

For reprint information, email prp@patientresource.com.

► Message from Jack West, MD



## SURVIVORSHIP, YOUR PATH FORWARD

### ➔ When it comes to survivorship

*plans, one size doesn't fit all. And, just like your treatment regimen, your survivorship plan should be designed uniquely for you. I encourage you to play an active role in developing and following your path.*

*Be comfortable with your medical transition team. If you don't have a doctor who is able and available to answer your questions and will include you in the decision-making process, find one. If you are considering getting a second opinion about a possible recurrence or a second cancer, do. The stakes are high. A second opinion will confirm what you've already been told or it will give you new options to consider. No single doctor or hospital is the best for every person's individual needs.*

*Seek out information from credible sources. In the past, patients received information primarily from their doctors. As a result of the explosion of information we've seen in the last 5 or 10 years, we now have oncology resources online that are both informative and interactive. This more social network model, where doctors, patients, family members and caregivers connect and share information, allows people to learn what survivorship means from a variety of sources. You can research best practices to find out why your medical team thinks the way it does, and you can join support groups to learn what does and doesn't work for other survivors. When equipped with the right tools, patients, their families and their caregivers can be remarkably sophisticated.*

*Different strategies work for different people. With the right tools, you can be comfortable with a survivorship plan that works for you.*

*Howard (Jack) West, MD, is the Associate Clinical Professor, Medical Oncology, and Executive Director, Employer Services, City of Hope Comprehensive Cancer Center, as well as President & CEO, Global Resource for Advancing Cancer Education (GRACE).*

## Survivorship transition brings challenges and opportunities

**N**o two cancer survivors are alike because every person's experience with the disease is unique. The term "survivor" means different things to different people, but it commonly refers to anyone who has lived with, through or beyond cancer. So whether you've completed active treatment and are disease-free or are living with metastatic cancer, this guide is designed for you and your loved ones.

### *You're among millions of fellow survivors*

As of January 2019, there were an estimated 16.9 million cancer survivors in the U.S., according to the National Cancer Institute's Office of Cancer Statistics. More than two out of three survivors were five years or more beyond their original diagnosis, and nearly one in five had been diagnosed 20 or more years earlier. Advances in early detection, innovations in treatment options and improvements in side effect management can be credited with the increasing number of survivors.

### *Expect the unexpected, and be patient*

Survivors are often surprised to learn that cancer-related issues frequently aren't resolved with the end of treatment. Recovering from cancer – physically, emotionally and mentally – can take a great deal of patience and more time than many survivors and their families expect. Treatment-related side effects, such as fatigue, chronic pain and cognitive dysfunction (chemo brain), can last for weeks, months or even years (see *Late Effects*, page 6). You may also experience emotional changes that can range from relief and gratitude to fear and anxiety (see *Emotional Late Effects*, page 8). Many options are available to alleviate and manage these issues, so it's essential to stay in frequent contact with your health care team post treatment.

As you make the transition from active treatment to post treatment (or continue treatment to stop/slow disease progression), you may find it challenging to step back into the life you had before your diagnosis. The first few months in particular will be a time of change, as you may need to make temporary or permanent adjustments concerning your level of activity, schedule, education or career, diet, finances, retirement plans or other aspects of your life (see *Life After Cancer*, page 4). Change isn't always easy and doesn't happen overnight, so be kind to yourself as you learn to adapt.

### *Resuming your prior routines*

You might have originally planned to celebrate when active treatment is completed, and now your brain is playing tricks on you. You may fear that having a party could jinx the cancer into recurring. This is a common reaction. Also, because you are looking at the world with a different lens now, you may feel differently about what was important to you before your cancer diagnosis to what you believe now is



### ANNUAL CELEBRATION SPOTLIGHTS SURVIVORS

➔ Every year on the first Sunday in June, cancer survivors, loved ones, cancer advocates and health care professionals across the U.S. celebrate National Cancer Survivors Day by participating in community events. The goal of this inspirational day, themed "A Celebration of Life," is to increase awareness about the ongoing challenges of cancer survivorship. It's a chance for everyone who has lived with cancer to observe the milestones they've reached and recognize those who have supported them along the way. Learn how to get involved and discover more cancer survivorship resources at [www.ncsd.org](http://www.ncsd.org).

more important post-cancer treatment. This can be very confusing for family, friends and co-workers. So anticipate the need to explain to others that this has been a life-altering experience, where you see your priorities today, and why. Don't expect to jump into the routine you had before you were diagnosed with cancer. Resuming activities may take time. Be patient as you adjust to your new life as your priorities may have changed.

### *Change can bring new opportunities*

Survivorship and the self-reflection that often accompanies it can open up opportunities for new experiences and different choices. Seek these out and embrace them. Above all, recognize that you are not alone. Many larger cancer centers and community treatment centers provide survivorship clinics and programs for adults who've had cancer treatment, or you can search online for one. Consider joining a cancer support group that meets in-person or online to share your experiences with and learn from other survivors. Your nurse navigator or a cancer support organization can provide a list of resources.

Your quality of life after cancer should be a continuing, lifelong focus. As you write this next chapter of your life story, remember there are resources available to you and fellow survivors who are ready to offer insight, friendship and support along the way. ■

## Defining Survivorship / Cancer survivorship is sometimes described in phases:

▶ **Acute survivorship** starts at diagnosis and ends when you finish initial treatment. The focus is on treating the cancer and minimizing or managing side effects.

▶ **Extended survivorship** spans the months and years following initial treatment. The focus is on monitoring for symptoms of late effects or signs of a recurrence or second cancer; treatment continues for those with chronic disease to stop/slow progression, maintaining quality of life.

▶ **Long-term survivorship** is when years have passed following initial diagnosis and treatment. The focus is on annual/periodic follow-ups and addressing any major health issues developing as a result of treatment.

## Creating a plan can help you define your goals moving forward

**M**any cancer advocacy organizations recommend a survivorship care plan for all cancer survivors, whether you are disease-free or living with chronic or metastatic cancer. Ideally, your survivorship care plan starts at the time of your diagnosis. This means making your life goals known to your treatment team so they can consider them in the treatment planning process. For example, if you are in your thirties, newly married and hope to have a family, fertility preservation should be explored before you start the therapies you will take to treat the cancer or prevent recurrence.

If the follow-up care plan you received does not include recommendations for survivorship care, your doctor, nurse navigator or case worker can help you make one. The information on this page should be included in your plan. Visit [PatientResource.com/Survivorship-Plan.pdf](http://PatientResource.com/Survivorship-Plan.pdf) to download these tools to help you get started:

- Survivorship Diagnosis Care Summary
- Follow-up Care Plan

### Your medical history

This information may include diseases, conditions or disorders; surgeries and treatments; hospitalizations; pregnancies; major accidents or injuries; past and present pain issues; lab reports and test results; immunizations; past and current medications; and ongoing health conditions. Include your family medical history.

**TABLE 1**  
**POTENTIAL SECOND CANCERS AMONG ADULT SURVIVORS**

Primary cancer	Most common second cancers
Bladder	Lung, bladder*, renal pelvis/ureter, pancreas, larynx, prostate
Breast (women)	Breast*, colon, esophagus, ovarian, stomach, thyroid, uterine
Colon	Colon*, anal, bile duct, kidney, rectal, small intestine, stomach
Hodgkin Lymphoma	Leukemia, breast (women), lip and tongue, lung, non-Hodgkin lymphoma, salivary gland, thyroid
Melanoma**	Melanoma*, other skin cancers, salivary gland, small intestine, breast (women), prostate, kidney
Testicular	Testicular*, bladder, kidney, pancreas, rectal, thyroid

\*Second primary cancer in the same organ/site as the first (not a recurrence)  
\*\*Learn how to detect a melanoma at [patientresource.com/ABCDErule.aspx](http://patientresource.com/ABCDErule.aspx)

**TABLE 2**  
**RECOMMENDED GUIDELINES FOR CANCER SCREENINGS**

Cancer type	Type of screening	Age	Frequency
Breast	Breast self-exam (women) Mammogram (women)	20+ 40-44 45-54 55+*	Regularly Optional Annually Every 2 years
Cervical	Pap test Pap test with a human papillomavirus (HPV) test	21-29 30-65	Every 3 years Every 5 years
Colorectal	Colonoscopy	45-75 76-85	Every 10 years Discuss with your doctor
Lung**	Low-dose computed tomography (LDCT) of the chest	55-74	Annually
Prostate	Prostate-specific antigen (PSA) blood test (discuss pros and cons of testing with your doctor)	50***-70	Varies based on PSA level

\*If you are healthy and expect to live another 10+ years, continue screening.  
\*\*Only if you meet all criteria: in relatively good health; smoking history of 30 (or more) pack-years (number of packs of cigarettes smoked daily multiplied by years of smoking); and smoke currently or quit within the last 15 years.  
\*\*\*Ask your doctor about starting screening at age 40 if your father or brother had prostate cancer before age 65 or if you are African-American.

### List of health care team members with contact information

Include each person's role, from primary care physician and medical, surgical and radiation oncologists to your follow-up care physician.

### Diagnosis

Make sure it includes cancer type, subtype and tumor site(s); stage or classification; date of diagnosis; diagnostic test results and pathology reports; and, if applicable, tumor grade, molecular biomarkers present, genetic test results, hormonal status and a summary of second/third opinions. (Review this information with your doctor, nurse practitioner or nurse navigator to ensure you have recorded it correctly. It is easy to confuse stage and grade.)

### Treatment summary, including dates

- Hospital stays: Reasons, medications, recovery time and any complications.
- Surgeries: Types, inpatient or outpatient, recovery times and any complications.
- Radiation therapy: Type, site(s) and total amount of radiation.
- Drug therapies: Type, drug names, dosages, duration, side effects and responses.
- Supportive care (palliative care): Symptom management, medications (such as for anxiety, nausea, etc.), pain management, counseling or other support services for you and/or your loved ones.
- Additional services: Physical or occupational therapy, fertility preservation, nutritional counseling, etc.

### Follow-up care plan

- Follow-up appointment schedule for ongoing monitoring.
- Maintenance medications or therapies, including type, dosage, frequency and duration.
- Referral(s) for cancer rehabilitation services, such as physical or occupational therapy, speech therapy, a lymphedema specialist or others.
- Information about your risk of a recurrence; a second cancer (see Table 1), long-term treatment-related side effects and late effects (see *Late Effects*, page 6).
- Recommended screening guidelines for other types of cancer (see Table 2), and ask your doctor how they apply to you.

### Health, wellness and lifestyle recommendations

These recommendations may include good nutrition habits, getting to or maintaining a healthy weight, improving fitness and increasing strength, and healthy lifestyle changes such as smoking cessation and stress management, with contact information for specialists to guide you.

### Your life goals

These life goals were previously identified and shared with your treatment team. Determine if you are still on track for accomplishing them. Create a plan for how to achieve them. Also consider adding some new goals (see *Life After Cancer*, page 4).

### Survivorship support and community resources

The resources should include your cancer center; survivorship clinics, support groups, cancer advocacy organizations and other local or area resources; survivor phone buddies and peer-to-peer matching; and online survivorship support groups and communities. ■

# SURVIVING TWO CANCERS IS THIS RUNNER'S ULTRAMARATHON



→ *Running close to 500 races after turning 40, Helene Unger celebrated her 50th birthday with a 50-mile ultramarathon. Triumphant, newly married and the picture of health, she never dreamed she'd soon be diagnosed with blood clots, a hereditary cancer syndrome and two types of gynecologic cancer.*

→ **My passion for running came later in life.** I threw myself into it with my usual enthusiasm—bordering-on-obsession and got hooked. Soon I was running races every weekend from spring through fall. Almost a decade later, I marked my 50th birthday with a 50-mile race.

Intensive training for this ultramarathon honed my physical and mental endurance to “go the distance.” It proved invaluable later that year when my life veered completely off course.

When I began training for another ultramarathon, my whole body seemed “off.” My legs felt heavy and sometimes swelled. I had lots of breathing issues and was so, so tired. Figuring I was out of shape, I doubled down on training, pushing myself even harder.

That strategy soon put me in the emergency room with chest pains that scared me. Tests detected multiple blood clots in my lungs and two in my left leg. Other quirky symptoms that should have been red flags were severe constipation, weird abdominal bloating and constant spotting between periods.

Within 10 days, I was back in the ER screaming from pelvic pain. This ultimately led me to a gynecologic oncologist and surgery to find out if the cysts found on my ovaries were cancerous. The two-hour procedure I’d anticipated lasted more than five hours. After discovering both ovarian and endometrial cancers, they had to perform a complete hysterectomy and remove lymph nodes in my upper right leg and groin area.

I was devastated. My 6’6” teddy bear of a husband, Gregg, and I were barely past our first wedding anniversary. Cancer and sudden menopause didn’t exactly fit with the rosy picture I’d imagined for our early marriage.

Both cancers were caught early, Stage I, and genetic testing was strongly recommended because my dad died at 60 of non-Hodgkin lymphoma, and my mother lives with metastatic breast cancer. I learned I have Lynch syndrome, a hereditary condition that puts me at significantly higher risk of developing colorectal cancer and at risk for ovarian, endometrial and some other cancers.

Standard of care was six rounds of chemotherapy, so I rang in the new year watching clumps of frosted hair fall into the sink. Chemo was tough. Gregg made it bearable by appealing to the

runner in me, treating chemo like a long-distance race. He kept saying, “You can do this, Helene, because you’ve done it before,” to remind me I’d been strong enough to get through an ultramarathon, so I was strong enough to get through anything.

He never missed a treatment. Family and friends visited, too, including a breast cancer survivor in a pink wig. I sported a teal wig to celebrate our cancer sisterhood. Another great comfort was my Goldendoodle, Jax, who rarely left my side at home.

We celebrated my final round of chemo over cake with family and friends. I’d so looked forward to that day, expecting everything would go back to normal. I couldn’t have been more wrong. The end of treatment was when emotional issues really started to pack a punch. Everyone thought I should be happy to be alive, but instead, I was terrified to live.

I was anxious and depressed, scared at times, struggling with memory loss and unable to focus. With my bald head, scarred abdomen and 20 extra pounds from steroids and inactivity, I didn’t look or feel like me. How could I ever blend back into the world, be a good friend and work with the energy and confidence I once had when I couldn’t even reconcile myself to the changed woman in the mirror?

My recovery turned around with the help and support from my treatment facility, a weekend with my mom at an ocean-side retreat house and getting to know many kind, strong and incredibly inspiring women through the National Ovarian Cancer Coalition. Opening up to each other to talk about our feelings and fears made such a difference. We share our hearts, our stories and our time to help raise awareness so other women pay attention when their bodies signal “the whisper” of ovarian cancer. In November, I’ll run with Team Teal in the New York City Marathon in memory of two very special Teal Sisters.

Nearly three years later, I’m back on my game and feeling great. Having Lynch syndrome means I go for more frequent preventive cancer checkups, but cancer-related appointments and follow-ups have become just another part of my routine.

I don’t dwell on my cancer experience, but I don’t forget it either. So yes, I’m a cancer survivor ... and so much more. ■

## The road through survivorship leads to many changes and opportunities



nce you move into survivorship, it's important to continue to be proactive about your health, including making and keeping regular follow-up appointments.

These appointments also give you the opportunity to keep the lines of communication with your doctor open as you transition back into former activities and explore new ones.

Regular monitoring will help your doctor detect warning signs of a recurrence or a second cancer so early treatment is possible (see Table 1, page 2). All of the detailed information you share with your doctor can be vital to monitoring you for other cancers and to manage any long-term side effects. Be sure to tell your doctor how you're feeling physically, mentally and emotionally, and include the following.

- New or ongoing pain that isn't adequately relieved
- New or ongoing physical symptoms, including bladder/bowel control; deep fatigue or insomnia; sexual dysfunction or lack of desire; mobility issues; signs of infection; tingling or numbness; fluid buildup; or changes in appetite, sense of taste, vision or hearing
- Cognitive (thinking-related) symptoms, such as difficulties with memory, concentration, processing information, word-finding or completing tasks
- Emotional issues: depression, anxiety, fear, anger, grief, hopelessness, emotional numbness, feeling overwhelmed or other concerns
- New medications, over-the-counter remedies, vitamins, supplements or herbs
- Visits to the emergency room, urgent care or other doctors, even if not cancer-related

### Making smart lifestyle decisions

Eating right and exercising continue to offer multiple health benefits and help you build a solid foundation for going forward with life. It may be helpful to consider nutrition and exercise as treatments your body needs to continue to be well. Remember, you're in control of the choices you make about nutrition and exercise, and smart choices will help you live the healthiest life possible.

Healthy eating after treatment may help reduce the risk of cancer recurrence or secondary cancers. It also assists you with improving other health conditions you may have, such as obesity, heart disease and diabetes, which have been linked to cancer. Maintaining a healthy weight is important for survivors, especially if treatment caused you to lose or gain weight. Whether you are trying to lose, gain or maintain, make sure to eat the essential nutrients, including carbohydrates, fats and protein.

You might consider nutritional counseling with a qualified professional, such as a registered dietitian. Together, you can create a nutrition plan and discuss any nutrition concerns you have. If there isn't a dietitian on your medical team, ask your doctor or nurse navigator for a referral.

Another healthy lifestyle choice for survivors is being physically active. After treatment ends, consult your doctor, who may suggest specific exercises, intensity levels and duration of activities, all based on your unique circumstances. Even a 10-minute daily walk can energize you and offer multiple health benefits, such as reducing anxiety, depression and fatigue. Physical activity is also a great way to

reduce stress, which is important to your overall health. And, it's a natural way to boost your mood, offering drug-free relief for many of the emotional side effects of cancer and its treatment.

### Returning to work or school

If you had to quit working or cut back your hours while you were in treatment, you may consider going back to work. Keep in mind that you may be dealing with long-term effects that might require temporary adjustments, such as a flexible schedule, reduced hours, a redesigned work station, the ability to work from home and/or altered responsibilities. Work with your supervisor to evaluate your workload or reassign duties as needed.

You may choose to find a new employer or a different line of work than you did before treatment began. You may feel self-conscious about why you're making a change but what you share is up to you. The Americans with Disabilities Act (ADA) prohibits current and future employers from asking about your medical history.

If you are going back to school, consider visiting the school or campus before returning. Maintain open communication and request additional resources from the school, such as emotional and social support, to help transition between treatment and school. Be sure to address learning or classroom difficulties early.



*“I was diagnosed in the dark ages of mesothelioma. Today, many more people are living with cancer ... and there is hope. I volunteer with The Mesothelioma Applied Research Foundation and Friend for Life Cancer Support Network so others going through mesothelioma won't feel as alone as I did.”*

~Heather Von St. James,  
mesothelioma survivor

### Giving back

Consider volunteering to talk with other survivors in person, on the phone or online. Your experiences can be of great value to someone else and may offer them a sense of hope.

Many volunteer opportunities exist for survivors. Ask family members, friends and others in your community network whether they know of an individual or organization that could benefit from your help. Or you may also want to call local hospitals, cancer centers or advocacy groups and ask how you can get involved. Some survivors find an organization related to their cancer to participate in fundraising events.

Sometimes giving back can be as simple as sharing your personal experience with cancer. A survivor once said, “As survivors, none of us fight alone.” Many patients depend on the survivor community to educate, support and engage them before, during and after treatment. Reach out to your advocacy group of choice to find out if you can share

your story with others. If you're interested in sharing with other readers of Patient Resource guides, email us at [editor@patientresource.com](mailto:editor@patientresource.com).

### *Re-evaluating finances and retirement*

Cancer-related costs can add up quickly. The financial coordinators at your hospital can work with you to address your financial concerns and determine if you qualify for government assistance. Social workers, advocates, financial counselors and patient navigators at your medical facility can also refer you to organizations and charities that may be able to help.

Before you were diagnosed with cancer, you may have had plans for retirement or a strategy for it. However, treatment expenses and time off work may have caused you to dip into or deplete your retirement funds. You may decide to go back to work either full time or part time to rebuild your savings.

If you plan to continue working, consider some changes when it is time to select your health insurance coverage for the next calendar year. You will likely have more doctor's visits and more tests (and possibly more prescriptions) than you did before your diagnosis of cancer. Read the fine print and determine if you want to choose a different coverage plan that may be a higher premium each month but covers more services and has a lower co-payment and deductible.

### *Reframing your life*

Having cancer often changes your perspective on life. The priorities you had before your cancer diagnosis may have changed during or after treatment ended. Your life goals may have changed or need to be redefined. You may reconsider the work you do and what you want out of life. There may be things you've always wanted to try or places to see.

Some strategies you can use to reassess your life include journaling, speaking with a counselor or spiritual leader, or asking your health care team about specialized support groups or services for cancer survivors.

### *Reclaiming your sexual health*

You may face post-treatment sexual difficulties, such as a decreased sex drive, the inability to achieve or maintain arousal, pain during intercourse or the delay or absence of orgasm. Many factors can cause these difficulties. Your doctor may look for physical factors that contribute to these issues, including high blood pressure or diabetes. Sometimes controlling these can correct the problem.

Cancer treatment may also be the cause. The most common physical sexual problem among male cancer survivors is erectile dysfunction (ED), which is the inability to get and/or maintain an erection. Treatment for ED often combines medication with physical and psychological elements.

The most common sexual problems that affect female survivors include vaginal dryness and discomfort, as well as pain during intercourse. Correcting these problems can help boost sex drive, arousal and ability to reach orgasm. Remedies include vaginal dilators, low-dose vaginal estrogen, lubricants, moisturizers and pelvic floor physical therapy.

Don't be embarrassed to bring up changes in your sexual health with your doctor so that your concerns can be addressed. Also, share your concerns with your partner and allow your partner to do the same. You could talk about ways to be intimate other than with intercourse. Do your best to set aside one-on-one time with your partner

to rediscover and strengthen the intimacy in your relationship. Depending on your situation, consider a discussion with a professional counselor or therapist. ■



## KEY TAKEAWAYS



- ▶ **Keep the lines of communication open with your doctor after treatment ends. Address any new symptoms right away.**
- ▶ **Keep follow-up appointments so your doctor can monitor you because sometimes you may not actually feel symptoms.**
- ▶ **Eat right and exercise for optimal health. Consider nutritional counseling with a registered dietitian.**
- ▶ **If returning to a job or school, address any adjustments that may be needed. When returning to work or starting a new job, read the fine print of your health insurance policy to select the plan that's best for your needs.**
- ▶ **Take time to evaluate your priorities after cancer because they may have changed.**
- ▶ **Ask for a referral to a financial counselor to determine if you are eligible for assistance.**
- ▶ **Consider sharing your experience with other survivors. It can be healing for them as well as you.**
- ▶ **Don't be afraid to bring up sexuality issues with your doctor. Treatments and therapies are available to help with this important part of your life.**



### **You or a loved one have been handed a devastating diagnosis**

**You need to find a resource that explains your diagnosis and treatment options in words you can understand.**

**Imagine having the opportunity to ask questions of professionals, and connecting with others who are having the same struggles. Imagine being able to support and learn from one another.**

### **This is cancerGRACE**

EDUCATION IS MEDICINE  
CANCERGRACE.ORG  
INFO@CANCERGRACE.ORG  
888.501.1025



## Be alert for side effects that may develop long after treatment ends

**F**or some survivors, completing active treatment may bring a particularly challenging time in their lives to a close. Side effects from therapies they received may disappear within weeks as their bodies slowly recover and heal. Other survivors, however, experience long-term side effects or medical conditions that can develop months or years after their treatment has ended. These are known as “late effects.”

Chemotherapy, hormone therapy, immunotherapy and targeted therapy are systemic therapies, which means the drugs travel in the bloodstream through the entire body. Late effects resulting from these treatments depend on the particular drug and how the body reacts to it. With surgery and radiation therapy, late effects typically involve only the area of the body that was treated.

Late effects can be hard to predict and vary widely from person to person depending on many factors. These can include the type of treatment, the specific drug and dosage and the length of time it was given, as well as the individual’s age, gender and overall health status. Some late effects disappear over time, while others may be permanent. Some can even develop without warning years later.

Ask your doctor or nurse navigator about late effects to watch for, including major health conditions that may be associated with the specific treatments you received or are receiving currently. Most late effects can be treated more easily and with a better outcome if they’re detected early. That’s why it’s so important to stick to the appointment schedule recommended in your follow-up care plan and to contact your doctor between appointments with any new health concerns.

**Immune-related adverse events (irAEs)** aren’t common, but they can occur with some types of immunotherapy. These irAEs are conditions that can develop rapidly, becoming serious and even life-threatening without swift medical attention (see Table 1). Immunotherapy can sometimes overstimulate the immune system, which can cause inflammation in a variety of systems in your body. You may not physically feel the symptoms of an irAE at first, but it may be diagnosed through routine lab tests or X-rays performed during follow-up visits. Attending all appointments for ongoing monitoring is crucial if you’ve received immunotherapy. Many of these treatments are relatively new, so the long-term effects are not yet well known. Remain alert to the possibility of irAEs for up to two years after treatment, and report

symptoms immediately to your doctor. Tell all medical professionals you see from now on that you’ve received immunotherapy.

Following are some of the more common late effects of cancer treatments.

**Bone loss** can be caused by many types of therapies as well as the cancer. These treatments can cause loss of bone mass and density, making bones thinner, brittle and porous. Bone loss also occurs when cancer has spread to the bone (metastasis). Your doctor can measure bone loss by comparing your current bone density scans with those taken during treatment. Medication or external-beam radiation therapy may be recommended to help relieve symptoms.

**Cognitive dysfunction** (chemo brain) is a term cancer survivors use when they can’t think clearly or have trouble processing information, remembering names and dates, finding the right word, concentrating and organizing their thoughts or tasks. More than one-third of survivors experience cognitive issues long after treatment ends, sometimes for years. Be patient with yourself, and consider talking with other survivors for insight and support. And though it has been nicknamed “chemo brain,” individuals who did not have chemotherapy as part of their cancer treatment also report these symptoms. It can result from other types of cancer treatment or from stress.

**Fatigue**, or feeling physically exhausted, continues long beyond the end of treatment. It occurs primarily because the body needs extra energy to repair healthy tissues damaged by cancer therapies. Different from the fatigue that healthy individuals feel, it lasts longer, is more severe and may be unrelieved by sleep. Talk to your doctor if fatigue is persistent enough to interfere with your day-to-day activities.

**Heart disease** and related conditions can be worsened by various cancer treatments. You are especially vulnerable if you had heart or vascular conditions before you began treatment. Heart disease broadly refers to coronary artery disease, congestive heart failure, arrhythmia (irregular heart rhythm) and heart attack. Related conditions include high blood pressure, stroke and blood clots. It’s important to talk to your doctor to help determine your level of increased risk, based on the types of therapy, specific drugs and dosages you received, and for how long. You may be referred to a cardiologist for additional long-term monitoring. You can help reduce your increased risk of heart disease by following the recommended nutrition guidelines for cancer survivors,

**TABLE 1**  
**IMMUNE-RELATED ADVERSE EVENTS (irAEs)**

Body System	irAE	Symptoms and Signs
Cardiovascular	Myocarditis	Chest pain, shortness of breath, leg swelling, rapid heartbeat, changes in EKG reading, impaired heart pumping function
Endocrine	Endocrinopathies	Hyperthyroidism, hypothyroidism, diabetes, extreme fatigue, persistent or unusual headaches, visual changes, alteration in mood, changes in menstrual cycle
Gastrointestinal	Colitis	Diarrhea with or without bleeding, abdominal pain or cramping, bowel perforation
Liver	Hepatitis	Yellow/orange-colored skin or eyes (jaundice), nausea, abdominal pain, fatigue, fever, poor appetite
Nervous system	Neuropathies	Numbness, tingling, pain, a burning sensation or loss of feeling in the hands or feet, sensory overload, sensory deprivation
Neurologic	Encephalitis	Confusion, hallucinations, seizures, changes in mood or behavior, neck stiffness, extreme sensitivity to light
Pulmonary/lung	Pneumonitis	Chest pain, shortness of breath, unexplained cough or fever
Renal/kidneys	Nephritis	Decreased urine output, blood in urine, swollen ankles, loss of appetite
Skin	Dermatitis	Rash, skin changes, itching, blisters, painful sores



including limiting how much red and processed meat you eat. A great way to start is to try going meatless a few days a week and incorporate other healthy protein sources into your meals.

**Infertility** can arise when cancer or its treatments damage any part of the endocrine system, including the adrenal glands, thyroid, ovaries, testes or the area of the brain that controls this system. Infertility may be temporary (months or even years), or it may be permanent. Because chemotherapy and radiation therapy are known to damage reproductive cells, people who have these treatments are at greater risk. Typically, the higher the treatment dose and longer the duration, the longer the period of infertility.

## Survivors can thrive from rehabilitation services



**Rehabilitation care** helps cancer survivors improve their physical strength, function and movement, which increases their ability to care for themselves and assist in the management of pain and other symptoms. A cancer rehabilitation team is typically supervised by a physiatrist (a doctor who specializes in rehabilitation) and may include physical and occupational therapists, rehabilitation nurses, speech therapists, mental health professionals, lymphedema specialists, dietitians and others.

Although some level of rehabilitation services and treatment would benefit most survivors, very few are actually referred to rehabilitation. In recent years, however, more emphasis has been placed on making rehabilitation services more readily available. In 2012, the Commission on Cancer (CoC), a nonprofit group overseen by the American College of Surgeons, made the availability of a rehabilitation program a mandatory requirement for a cancer center to receive accreditation. In 2016, the same group published "Ensuring Patient-Centered Care" in its Cancer Program Standards. It included a set of policies and procedures designed to ensure patient access to rehabilitation services either onsite or by referral.

Ask your doctor about how a rehabilitation program may help you work toward regaining your physical health, achieving mental and emotional well-being and feeling better equipped to be more self-reliant.

## LYMPHEDEMA

Signs and symptoms of lymphedema can range from mild to severe and may include swelling in an area such as an arm or a leg, a heavy sensation in the limb, tightness and reddening of the skin and decreased flexibility.



©Patient Resource LLC

**Lymphedema** may occur when lymph nodes are surgically removed or damaged during surgery or by radiation therapy, infection or the cancer itself. Lymph fluid can build up and cause swelling in that area, extending to the arms, legs, face, neck, abdomen or genitals. The affected part of your body may feel tight or hard or you may notice tingling, discomfort and less flexibility. Contact your health care team at the first sign of swelling, and keep the swollen limb elevated whenever possible. Your doctor may recommend wearing a compression garment that has been properly fitted by a certified lymphedema specialist.

**Neuropathy** is pain or discomfort resulting from damage to the peripheral nervous system, which controls movement and feeling in the arms and legs. Symptoms include numbness, pain, burning, tingling or loss of feeling in the hands or feet. Many types of cancer treatment can cause neuropathy. Discuss your symptoms with your doctor, who may prescribe pain medication, steroids, numbing creams or lotions to help provide relief.

**Neutropenia** (low white blood cell count) can be caused by chemotherapy. It puts the body at higher risk for developing an infection. If your treatment plan included chemotherapy, your doctor will likely schedule regular blood tests to monitor for it. If a high fever accompanies the condition or if your white blood cell count is extremely low, your doctor may prescribe treatment to stimulate your bone marrow to produce more white blood cells.

**Pain** can be caused by several types of cancer treatment. It typically lessens as your body heals and recovers. Pain can also result from other side effects of cancer and its treatments, including peripheral neuropathy, nerve damage, osteoporosis, lymphedema, bone metastasis, hormone imbalance or loss of motion. Untreated pain, even if minor, can escalate quickly and get out of hand. Many pain management options are available, so contact your doctor at the first sign of pain. Provide as many details as you can, noting when pain occurs, for how long and noticed triggers.

**Sexuality issues** can develop as a result of the cancer and its treatment, which can affect how you feel about your body and how you relate intimately to your partner (see *Reclaiming your sexual health*, page 5, to learn more). Your sexual health contributes to your quality of life, so even if you feel awkward, talk to your doctor about any sexual difficulties you're experiencing. ■

## COMMON LATE EFFECTS BY TREATMENT TYPE

### CHEMOTHERAPY

- ▶ Bone loss
- ▶ Cognitive problems
- ▶ Constipation
- ▶ Diarrhea
- ▶ Fatigue
- ▶ Fever
- ▶ Infertility
- ▶ Neuropathy
- ▶ Neutropenia

### IMMUNOTHERAPY

- ▶ Cognitive problems
- ▶ Fatigue
- ▶ Fever
- ▶ Immune-related adverse events (irAEs)\*
- ▶ Skin reactions

\*See Table 1, page 6, Immune-Related Adverse Events (irAEs).

### RADIATION THERAPY

- ▶ Bone loss
- ▶ Cognitive problems
- ▶ Diarrhea
- ▶ Fatigue
- ▶ Infertility
- ▶ Lymphedema
- ▶ Skin reactions

### SURGERY

- ▶ Cognitive problems
- ▶ Fatigue
- ▶ Infertility
- ▶ Lymphedema
- ▶ Pain
- ▶ Sexual issues

### TARGETED THERAPY

- ▶ Constipation
- ▶ Cough
- ▶ Diarrhea
- ▶ Fatigue
- ▶ Headache
- ▶ Shortness of breath or trouble breathing
- ▶ Skin reactions

## Recognizing and managing your post-treatment emotions

**Y**ou may be prepared for the possibility of managing the physical late effects of cancer treatment, but be aware of your ongoing emotional feelings as well. Mental and emotional health are an important part of the transition into survivorship. It is impossible to predict how survivorship will affect you because it is different for everyone, but many survivors admit to being surprised when they feel stress, depression, anxiety, guilt and/or fear rather than feelings of jubilation and relief.

Be gentle with yourself as your body and mind heal after cancer because a variety of intense and unfamiliar emotions may linger. Ask your doctor about the time needed for emotional healing. Be prepared to seek help if the feeling of being “off” doesn’t go away and if your emotions hinder your daily life. Various supportive care resources and services are designed to help you through this phase, including counselors and therapists with expertise in working with people living with cancer.

Following are common emotional effects you may experience after treatment ends. All are valid, understandable and even expected for cancer survivors, but they can become serious if ignored. Therefore, an important part of survivorship involves acknowledging your emotions — both the good and the bad.

**Anxiety** about your future can begin as soon as treatment ends and can continue until it is addressed. Moderate to severe anxiety is often treated with medication, therapy or a combination of both. Explore relaxation techniques, such as meditation, muscle relaxation, yoga or guided imagery. Peer-to-peer cancer support volunteers can offer insight into what to expect, and they’re often available by phone or online.

**Depression** is a psychological reaction to your situation as a whole. Certain ongoing treatments or maintenance therapies, such as chemotherapy or hormone therapy, can also cause or contribute to depression. Many cancer survivors do not talk to their doctors about it because they think depression is “expected,” but it can, and should, be treated. It’s extremely important to talk with your doctor about feeling hopeless, helpless, “numb” or worthless. If these feelings last more than a few days or if you have thoughts of death or of attempting suicide, seek medical attention immediately.

**Doubt** can lead to confusion and questions about the meaning of life and its purpose. Some people find strength in support from family, friends, the community or spirituality. It may also help to talk about your feelings with a counselor or support group.

**Fear** can continue after treatment because of the possible risk of a recurrence or secondary cancer. Making long-term plans may become difficult because every ache and pain triggers a concern that cancer has returned. Develop a comprehensive follow-up care plan to help calm these fears. Do your best to stay focused on the present.

**Guilt** may occur if you blame yourself for getting cancer because of actions you did or didn’t take, if you feel you’ve been a burden to loved ones or if you wonder why you survived when others with similar conditions didn’t. Talk with a therapist about these feelings. You might find

that you can lessen your guilt by giving back to the cancer community. Helping others can provide a sense of purpose and well-being that can help take away blame you may be placing on yourself.

**Scanzxiety** is the anxiety you may feel before having scans or tests to monitor your disease and while you’re waiting for the results, and it’s real. It can affect your ability to eat, sleep, work and more. Because your follow-up care requires frequent monitoring, it’s very important to find ways to manage it. Stay busy with activities you enjoy. Exercise daily, if possible. Call your doctor if your scanxiety prevents you from carrying out your daily activities.

**Stress** is the physical, mental and/or emotional tension that results from an adverse or demanding circumstance, such as cancer. It’s common for you to feel stress as you transition from patient to survivor, but watch for signs of post-traumatic stress (PTS). It can occur any time after treatment. Although PTS is not as severe as post-traumatic stress disorder (PTSD), the symptoms are similar. They include feeling defensive, irritable or fearful; inability to think clearly; difficulty sleeping; avoiding people; and losing interest in life. Survivors with PTS need early treatment, which may include medicines (antianxiety drugs or antidepressants), crisis intervention techniques (relaxation training and support groups) or cognitive behavioral therapy. ■



### THE ROLE OF THE CAREGIVER AFTER TREATMENT ENDS

➔ **Once your loved one** with cancer transitions away from their primary treatment schedule, your role as a caregiver also transitions. You will begin to adjust back to your previous lifestyle from before treatment began. Such a change can bring surprising emotions with it. It’s possible that more intense feelings may emerge because you may now have more time to process what’s happened. If you find the emotions are ongoing or overwhelming, consider talking with your own doctor or a mental health specialist.

It is common to remain worried that your loved one’s cancer will return. Attending post treatment follow-up appointments is both important for the survivor and the family/caregiver. Many people experience what is sometimes referred to as “scanxiety” as follow-up tests are conducted. Try to adopt the attitude that you’ll have time to worry later if you hear concerning news, and otherwise proceed as normal even when the time for these tests come around on your calendar.

Don’t be surprised if your loved one, or even yourself, find a desire to arrange priorities differently from before the diagnosis. Getting back to normal is great, and enhancing normal is good, too.

# Support and financial resources available for you

## CANCER EDUCATION

American Cancer Society.....	cancer.org
Cancer.Net (patient website of American Society of Clinical Oncology).....	cancer.net
CANCER101.....	cancer101.org
CancerCare.....	cancercare.org
CancerQuest.....	cancerquest.org
The Gathering Place.....	touchedbycancer.org
Global Resource for Advancing Cancer Education (GRACE).....	cancergrace.org
The Hope Light Foundation.....	hopelightproject.com
LIVESTRONG Foundation.....	livestrong.org
National Cancer Institute.....	cancer.gov
National Comprehensive Cancer Network (NCCN).....	nccn.org
NCI Contact Center (cancer information service).....	800-422-6237
OncoLink.....	oncolink.org
Patient Power.....	patientpower.info
PearlPoint Nutrition Services.....	pearlpoint.org
Scott Hamilton Cares Foundation.....	scottcares.org
Triage Cancer.....	triagecancer.org

## CAREGIVERS & SUPPORT

CanCare.....	cancare.org
CANCER101.....	cancer101.org
Cancer and Careers.....	cancerandcareers.org
CancerCare.....	cancercare.org
Cancer Hope Network.....	cancerhopenetwork.org
Cancer Information and Counseling Line.....	800-525-3777
Cancer Really Sucks!.....	cancerreallysucks.org
Cancer Support Community.....	cancersupportcommunity.org
Cancer Support Helpline.....	888-793-9355
Cancer Survivors Network.....	csn.cancer.org
Caregiver Action Network.....	caregiveraction.org
CaringBridge.....	caringbridge.org
Center to Advance Palliative Care.....	capc.org
Chemo Angels.....	chemoangels.com
The Children's Treehouse Foundation.....	childrentreehousefdn.org
Cleaning For A Reason.....	cleaningforareason.org
Cooking with Cancer.....	cookingwithcancer.org
Cuddle My Kids.....	cuddlemykids.org
Family Caregiver Alliance.....	caregiver.org
Fighting Chance.....	fightingchance.org
Friend for Life Cancer Support Network.....	friend4life.org, 866-374-3634
The Gathering Place.....	touchedbycancer.org
Guide Posts of Strength, Inc.....	cancergps.org
The Hope Light Foundation.....	hopelightproject.com
Imerman Angels.....	imermanangels.org
LIVESTRONG Foundation.....	livestrong.org
LivingWell Cancer Resource Center.....	livingwellcrc.org
Lotsa Helping Hands.....	lotsahelpinghands.com
The Lydia Project.....	thelydiaproject.org
MyLifeLine.org Cancer Foundation.....	mylifeline.org
National LGBT Cancer Project.....	lgbtcancer.org
Patient Empowerment Network.....	powerfulpatients.org
Patient Power.....	patientpower.info
Scott Hamilton CARES Foundation – 4th Angel.....	4thangel.org
SHARE Caregiver Circle.....	sharecancersupport.org/caregivers-support
Stronghold Ministry.....	mystronghold.org
Triage Cancer.....	triagecancer.org
Vital Options International.....	vitaloptions.org
Walk With Sally.....	walkwithsally.org
Well Spouse Association.....	wellspouse.org
weSPARK Cancer Support Center.....	wespark.org

## COMPLEMENTARY PROGRAMS & ALTERNATIVE MEDICINE

Believe Big.....	believebig.org
The Center for Mind-Body Medicine.....	cmbm.org
National Center for Complementary and Integrative Health.....	nccih.nih.gov
Office of Cancer Complementary and Alternative Medicine.....	cam.cancer.gov
Society for Oncology Massage.....	s4om.org
Stewart's Caring Place.....	stewartscaringplace.org
Touch, Caring and Cancer.....	partnersinhealing.net

## MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline.....	866-276-7443
--	--------------

## NUTRITION

American Cancer Society.....	cancer.org
CancerCare.....	cancercare.org
LIVESTRONG Foundation.....	livestrong.org
OncoLink.....	oncolink.org
PearlPoint Nutrition Services.....	pearlpoint.org
Physicians Committee for Responsible Medicine.....	pcrm.org/health/cancer-resources

## PAIN MANAGEMENT

American Chronic Pain Association.....	theacpa.org
American Society of Anesthesiologists.....	ashaq.org
LIVESTRONG Foundation.....	livestrong.org
The Resource Center of the Alliance of State Pain Initiatives.....	trc.wisc.edu
U.S. Pain Foundation.....	uspainfoundation.org

## SURVIVORSHIP

13-Thirty Cancer Connect.....	13thirty.org
A Time To Heal.....	atimetohelfoundation.org
American Cancer Society.....	cancer.org
American Childhood Cancer Organization.....	acco.org
Angel On My Shoulder.....	angelonmysoulder.org
Association of Community Cancer Centers (ACCC).....	acc-cancer.org
Bag It!.....	bagitcancer.org
Cancer ABC's.....	cancerabcs.org
Cancer and Careers.....	cancerandcareers.org
Cancer Hope Network.....	cancerhopenetwork.org
Cancer Support Community.....	cancersupportcommunity.org
Cancer Survivors' Fund.....	cancersurvivorsfund.org
Cancer Survivors Network (Online Community).....	csn.cancer.org
Cancer.Net (patient website of American Society of Clinical Oncology).....	cancer.net
CancerCare.....	cancercare.org
CancerQuest.....	cancerquest.org
Catherine Boulay Foundation.....	catherineboulayfoundation.org
Centers for Disease Control and Prevention.....	cdc.gov/cancer/survivors
Children's Cancer Research Fund.....	childrenscancer.org
Climb for Cancer Foundation.....	climbforcancerfoundation.org
The Cope Well Foundation.....	copewell.org
Fashion Fights Cancer.....	fashionfightscancer.org
Global Resource for Advancing Cancer Education (GRACE).....	cancergrace.org
Guide Posts of Strength, Inc.....	cancergps.org
Hope for Two...The Pregnant with Cancer Network.....	hopefortwo.org
Imerman Angels.....	imermanangels.org
Indian American Cancer Network.....	iacanetwork.org
Lacuna Loft.....	www.lacunaloft.org
Law Enforcement Cancer Support Foundation.....	lawenforcementcancer.org
LIVESTRONG Foundation.....	livestrong.org
National Cancer Survivors Day.....	ncsd.org
The National Children's Cancer Society.....	thenccs.org
National Coalition for Cancer Survivorship.....	canceradvocacy.org
National Comprehensive Cancer Network (NCCN).....	nccn.com
National LGBT Cancer Network.....	cancer-network.org
National LGBT Cancer Project.....	lgbtcancer.org
Nueva Vida, Support Network for Latinas with Cancer.....	nueva-vida.org
Ohio State The James Online Cancer Community.....	cancerconnect.com/thejames
Project Koru.....	athletes4cancer.org
Reel Recovery.....	reelrecovery.org
River Discovery.....	riverdiscovery.org
Scott Hamilton CARES Foundation – 4th Angel.....	4thangel.org
Scott Hamilton CARES Foundation – ChemoCare.....	chemocare.com
Stupid Cancer.....	stupidcancer.org
Survivor's Outdoor Experience.....	survivorsoutdoorexperience.org
Survivorship A to Z.....	survivorshipatoz.org/cancer
Triage Cancer.....	triagecancer.org
True North Treks.....	truenorthtreks.org
United Cancer Foundation.....	unitedcancerfoundation.org
Walk with Sally.....	walkwithsally.org
Women Survivors Alliance.....	womensurvivorsalliance.org

*This patient education guide was produced with support from:*

