

FREE take one

5th Edition

CANCER SURVIVORSHIP

A GUIDE FOR SURVIVORS AND THEIR FAMILIES

Moving forward with purpose

Feature Interview



Angela Gentile
Anal Cancer Survivor

“Helping others helps me”

Published in partnership with



Global Resource for Advancing Cancer Education

CANCER SURVIVORSHIP

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► *Message from Jack West, MD*

Empower yourself for survivorship

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.

Dr. West is the Executive Director of Employer Services and Medical Oncologist for City of Hope, Los Angeles, as well as President & CEO, Global Resource for Advancing Cancer Education (GRACE).

Patience and support set the stage for a promising future

P *people who face cancer* have stories that are as unique as they are, and they define survivorship in their own ways. Some people consider themselves survivors upon receiving a cancer diagnosis. Others take on the role once they have moved past active treatment. Still others prefer no label at all. No matter how you define it or where you are in your story, this guide is for you: the forward-thinking, strong person who is living with, through or beyond cancer.

Cancer survivorship is sometimes described in phases:

- Acute survivorship starts at diagnosis and ends when initial treatment is over. 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 because of treatment.

According to the Surveillance Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, the number of survivors is increasing. Approximately 16.9 million cancer survivors were counted in the U.S. in January 2019. By January 2030, it is estimated that number will be more than 22.1 million. Advances in early detection, innovations in treatment options and improvements in side effect management can be credited with the increasing number of survivors.

Preparing for your next phase

For many people, cancer-related effects don't often disappear when treatment ends. Recovery from the physical, emotional and mental aspects of cancer can take a great deal of patience and more time than many survivors and their families expect. This guide is designed to help prepare you for the path ahead. You may have challenges, and you may find new opportunities.

Though you may have originally planned to celebrate when active treatment was complete, you may be second guessing yourself. You may fear that having a party could jinx the cancer into recurring. Or, 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.

These feelings are common, and they can be very confusing for you as well as for your family, friends and co-workers. Don't expect to jump back into the routine you had before you were diagnosed with cancer. Resuming activities, or changing them entirely, may take

time. Be patient as you adjust to this next phase of your life. Be prepared to explain to others that this has been a life-altering experience and that some things, such as where you see your priorities today, may have changed.

Survivorship and the self-reflection that often accompanies it can pave the way for new experiences and different choices. Look for these and embrace them.

Some 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. There is still more to learn, and sharing your knowledge could offer hope to other survivors. Your nurse navigator or a cancer support organization can provide a list of resources.

Remember, you are not alone. Your community extends past active treatment. It can be a lifelong source of friendship and support. ■

Take advantage of all telehealth has to offer

Though you may have fewer and less frequent medical appointments during survivorship, you will still have them. Telehealth may offer you a convenient option for staying on schedule with these important visits.

Telehealth is the delivery of health care from a distance using technology such as computers, cameras, video conferencing, the internet and smartphones. You may hear it referred to as a "virtual appointment."

Virtual appointments are not designed to replace in-person visits and are not recommended for first-time visits. Instead, they are an alternative for later face-to-face visits. At this point in your cancer care, you have likely already developed a relationship with your oncologist, making this a possible option for you. You may consider telehealth for these reasons:

- ▶ You may hesitate to leave home because of an increased risk of infection.
- ▶ You may have a fever or not feel well.
- ▶ You may not have transportation.
- ▶ It may be difficult physically for you to get to an appointment.
- ▶ You may live far from the medical facility.

Ask your health care team if telehealth is available for you. To participate, you will only need a device, such as a smartphone, tablet or computer, and an internet connection. And don't worry if you don't consider yourself to be tech-savvy.

These appointments are conducted through patient portals or on another video or web conferencing platform. Typically, you will receive instructions in advance from your health care provider's office on how to prepare for the appointment.

Managing your health is easier when you have a plan

Just as you needed a treatment plan, you also need a survivorship care plan once therapy is finished or as you continue with maintenance therapy. By working together with your doctor, you can map out the level of care you will need, develop a follow-up schedule and learn about recommendations for living the best life possible.

Following are the common parts of a survivorship care plan. Your plan will be customized for you, taking into consideration your diagnosis and treatment history, age and other health conditions, as well as your expectations for the future.

Medical history

This information may include your diagnosis and other diseases 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. It also may include your family medical history.

Your diagnosis should include the 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.

- Your treatment summary should include the following:
- Hospital stays: Reasons, medications, recovery time and complications.
 - Surgeries: Types, inpatient or outpatient, recovery times and 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 or nausea), 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

This part of the plan will outline your follow-up care:

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

Contact information

Note the health care team members you will see for follow-up care, and include their contact information.

Health, wellness and lifestyle recommendations

These recommendations may include good nutrition habits, getting to or maintaining a healthy weight, improving fitness and increasing strength. Healthy lifestyle changes such as stopping smoking and managing stress are important to discuss.

Also ask your doctor about getting vaccinations, such as those for COVID-19, shingles or influenza. What is recommended for one person may not be appropriate for another, so be sure the doctor you talk with is familiar with your medical history and current treatments.

Life goals

You may have already shared these goals with your medical team when planning treatment. Now is also a good time to change them or add new ones that better fit in with where you are now.

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. ■

TABLE 1
▲ **POTENTIAL SECOND CANCERS IN ADULT SURVIVORS**

Primary cancer	Most common second cancers
Bladder	Lung, bladder*, renal pelvis/ureter, pancreas, larynx, prostate
Breast (women)	Breast*, colon, esophagus, ovary, stomach, thyroid, uterus
Colon	Colon*, anus, bile duct, kidney, rectum, 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	Testicle*, bladder, kidney, pancreas, rectum, 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

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

Cancer type	Type of screening	Age	Frequency
Breast	Breast self-exam (women) Mammogram (women)	20+	Regularly
		40-44	Optional
		45-54	Annually
		55+*	Every 2 years
Cervical	Pap test Pap test with a human papillomavirus (HPV) test	21-29	Every 3 years
		30-65	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.

➔ Visit PatientResource.com/SurvivorshipPlan.aspx to download a blank Survivorship Care Plan.

In the spring of 2017, social worker and author Angela Gentile was diagnosed with Stage III anal cancer at 51. She relied on her faith, family and friends to overcome the physical and emotional challenges associated with this rare disease.

Emotional Healing

An important step on the path to survivorship



➔ Who knew you could get cancer up the bum?

I didn't until a quick Google search about what I thought were stubborn hemorrhoid symptoms pointed to anal cancer. I saw my doctor the next day. I don't remember her exact words, but I'll never forget the look on her face after she performed a rectal exam. She'd felt a lump and found blood. She scheduled an urgent colonoscopy, along with a referral to a specialist. It was confirmed I had anal cancer. Because lymph nodes were involved, my diagnosis was Stage III.

The lump was a tumor that appeared to be growing quickly, so I was put on the fast track for treatment. The plan included two 96-hour treatments of infused chemotherapy through a pump and 30 rounds of pelvic radiation. Before I could start, however, a very painful perianal abscess appeared in my anal canal, and I had emergency surgery to clean it out.

Treatment affects everyone differently. I developed febrile neutropenia (high fever and low white blood cell count) and was hospitalized for a week. I'm fair-skinned, and I had a pretty severe reaction to the radiation. My radiation oncologist and her nurse gave me several suggestions for things to try and things to avoid. Sitting in my bathtub filled with baking soda four times daily was soothing. A topical antibacterial cream used to prevent infection in burns was most helpful.

I went into survivor mode. I have a close-knit support system at home in my husband, son and daughter. My daughter created a giant chart to make sure I stayed on schedule with meds, baths, etc. My dog, Rocky, was at my bedside constantly. As I was recovering, we welcomed a new puppy, Berkeley, into our lives. Caring for her ensured I got up and kept moving.

Cancer is a big revealer. I learned loud and clear to whom I mattered. The messages, flowers and little gifts I received from family, friends and colleagues were incredible. I turned toward my faith and was given advice that was exactly what I needed to hear at the time: Let God carry you through.

I also found support through Facebook groups. One was just for women, and we discussed the way anal cancer can impact a woman's health and lifestyle. I have what's referred to as collateral damage from the radiation therapy. Radiation beams aimed at the cancer can affect neighboring organs, such as the bladder, bowel and private parts, which has changed the way I'm able to do certain things. What

helps me most with these ongoing challenges is being upfront and honest with my general practitioner. When I have an issue, she refers me to the right person, whether it's a gynecologist or GI doctor. It's up to me to tell her if I'm having a problem. I have to be my own advocate. I'm not the same person because of that damage, but I'm working around it and am grateful for every day. Getting back on my bike for the first time was a huge turning point for me!

My treatment ended in August, and in November 2017, scans revealed I was NED (no evidence of disease). I have follow-up visits every six months and will continue to for five years.

Once treatment ended, life didn't just go back to normal like you might expect. During active treatment I'd been surrounded by a team of people constantly making sure I was okay. Suddenly, they were gone. I still wasn't able to go back to work or resume my volunteer activities. I felt like an empty shell and became clinically depressed.

I began taking medication. I also thought that, as a writer, a good solution would be to tell my story. I quickly realized that my story wasn't enough. I reached out on social media to ask if anyone whose life had been affected by anal cancer had a story to tell. The response was overwhelming. Patients, caregivers, loved ones — so many people had stories to tell, and I had a new purpose. I decided to write an anthology, a book composed of all their stories. I'd never written one, so I researched and learned how. I interviewed wonderful people and wrote stories filled with practical information. Some of the stories are hopeful; others are educational. The project was healing. It gave me a purpose not just as a survivor but as a human being. Even better, I could do all of it while I was lying on the couch recovering.

It took about nine months to finish and self-publish *Cancer Up the Wazoo: Stories, information and hope for those affected by anal cancer*. It's available on Amazon.com with a portion of every sale going to the Anal Cancer Foundation. I hope that hearing from the 25 people involved in the book empowers and inspires other people affected by anal cancer. Helping others tell their stories was a way to help me cope and heal. Now I'm able to close the book on that chapter of my life and move on with my "new normal." ■

Post-treatment: Forging a new path forward

Survivorship will bring about change in many areas of your life. You may have a more open schedule because you won't have as many medical appointments as you once did. You may feel ready to go back to work or school. You may be more independent, no longer needing the help of a caregiver. You may even feel ready to take on a caregiving role for your children, parents or other loved ones. Life will be different, and it can be very positive with the right approach.

Think about where you are in your life right now, and imagine where you'd like to be. It's like having a clean slate. There is no better time than now to figure out how you want to move forward.

Communicate openly and honestly

It's important to keep the lines of communication open with your doctor. All the detailed information you share with your doctor can be vital to monitoring you for other cancers and to managing 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 (often called chemo brain)
- 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

Make smart lifestyle decisions

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

Healthy eating after your treatment ends may help reduce the risk

SURVIVOR VOICE / ANNA W.



“I have a new appreciation for life. I keep a copy of my latest blood test with my tumor marker number on the wall of my office. When stressed, I stop and look at that number and realize that being alive is what really matters.”

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 registered dietitian. Together, you can create a nutrition plan and discuss your concerns. If there isn't a dietitian on your medical team, ask your doctor or nurse navigator for a referral.

Being physically active is an important lifestyle choice for survivors. After treatment ends, consult your doctor, who may suggest specific exercises, intensity levels and duration of activities, all based on your unique circumstances.

Don't fear that you will only get the benefits of exercise if you run a marathon. 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.

Return to work or school

Did you have to reduce your workload or take a leave of absence from work or school to accommodate treatment? If so, you might consider going back. But before simply resuming the same role and schedule as before, think about the following:

- You may have long-term effects that might require your employer to make 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 from what you had before treatment began. You may feel self-conscious about why you're making a change, but your reasons are your own and what you share is up to you. The Americans with Disabilities Act (ADA) prohibits current and future employers from asking about your medical history.
- Before going back to school, visit the school before returning, especially if you have physical limitations that may make it difficult to navigate the campus. Maintain open communication with the school administration and request additional resources, such as emotional and social support, to help transition between treatment and school. Be sure to address learning or classroom difficulties early.

Give back to the cancer community

“Giving back” can happen in many ways, and it doesn't have to take a lot of effort. Sometimes it is as simple as sharing your experience. Hearing how someone else navigated cancer can provide hope and help to another person, and many patients depend on the survivor community to educate, support and engage them before, during and after treatment.

Consider volunteering with a cancer support group to talk with other survivors in person, on the phone or online. 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 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.

If you're interested in sharing with other readers of *Patient Resource* cancer guides, email us at editor@PatientResource.com.

Examine your financial situation

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 do, 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 copayment and deductible.

Cancer-related costs can be confusing, and you don't have to figure them out on your own. The financial coordinators at your hospital can work with you to address your financial concerns and determine if you qualify for government or other types of 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.

Reframe your life's goals

You may have different priorities than you had before your cancer diagnosis. 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 you want to see.

You may decide to include your loved ones in this conversation, but remember, these are your life goals, so be true to what is in your heart. Use these strategies to help form your new perspective on your future:

- Write in a journal
- Meditate
- Speak with a counselor, life coach or spiritual leader
- Join a support group for cancer survivors

Reclaim your sexual health

A cancer diagnosis and its treatment can change many aspects of 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, the delay or absence of orgasm or feeling less desirable. Talking about these types of changes with your doctor or nurse is crucial and you should not be embarrassed to bring them up. Your sexual health is a vital part of life.

Many factors can cause these difficulties, and your doctor may look for physical factors that contribute to them, such as high blood pressure or diabetes. Sometimes controlling these can correct the problem.

A possible 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.

Sexual problems that may affect female survivors include vaginal dryness and discomfort, as well as pain during intercourse. Correcting these problems can help boost sex drive, arousal and the ability

to reach orgasm. Remedies include vaginal dilators, low-dose vaginal estrogen, lubricants, moisturizers and pelvic floor physical therapy.

Lastly, share your concerns with your partner and allow your partner to do the same. Do your best to set aside one-on-one time with each other to rediscover and strengthen the intimacy in your relationship. Explore ways to be intimate other than intercourse. 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.**
- ▶ **Eat right and exercise for optimal health. Consider these as types of treatment that you can control.**
- ▶ **Address any adjustments that may be needed when returning to work or school. When 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 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 for you.**
- ▶ **Don't be afraid to bring up sexual health 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
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888.501.1025



Plan for side effects that may appear after active treatment ends

The side effects that occur from treatment often disappear as your body heals. However, depending on the therapies in your treatment plan, you may experience long-term side effects or medical conditions that develop months or years after treatment ends. These are known as late effects.

Late effects can vary widely from person to person based on many factors, such as your age, gender and overall health status. How you are affected may also depend on the type of treatment you had, the specific drug and dosage, and the length of time it was given. 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 are determined by the particular drug and how the body reacts to it. Late effects from surgery and radiation therapy typically involve only the areas of the body that were treated.

Some late effects disappear over time, while others may be permanent. Some can even develop without warning years later. Because they can be so hard to predict, being aware of them is a good course of action.

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 survivorship care plan and to contact your doctor between appointments with any new health concerns.

Immune-related adverse events (irAEs) are not common but can occur with certain types of immunotherapy, so tell all medical professionals you see from now on that you've received immunotherapy. Ask your doctor if you are at risk, how to identify the symptoms and when to seek emergency care (see Table 1). Some irAEs can develop rapidly, becoming severe and even life-threatening without immediate medical attention. Report symptoms immediately if they occur. The side effects may be easily corrected if they are treated rapidly.

Making and keeping all medical appointments on schedule is very

important because routine laboratory tests and imaging may detect an irAE in its early stages before you can feel symptoms. Contact your health care team if symptoms arise between appointments. 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 completing immunotherapy.

Late effects can differ by treatment type (see Table 2, page 7). Following are some of the most common.

Bone loss can be caused by many types of therapies as well as the cancer itself. 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) occurs when cancer survivors can't think clearly or have trouble processing information, remembering names and dates, finding the right word, concentrating or organizing their thoughts or tasks. It is common to have these types of 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 is 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, can continue 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 it 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

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

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, including limiting how much red meat and processed food 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 the endocrine system. Infertility may be temporary (months or even years) or 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. Talk with your doctor or ask for a referral to a fertility specialist for more information.

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 that often begins 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.

TABLE 2
COMMON LATE EFFECTS BY TREATMENT TYPE

Treatment Type	Late Effect
Chemotherapy	Bone loss, cognitive problems, constipation, diarrhea, fatigue, fever, infertility, neuropathy, neutropenia
Hormone therapy	Blood clots, bone loss, hot flashes, menopausal issues, sexual health issues
Immunotherapy	Cognitive problems, fatigue, fever, irAEs*, skin reactions
Radiation therapy	Bone loss, cognitive problems, fatigue, infertility, lymphedema, skin reactions
Surgery	Cognitive problems, fatigue, infertility, lymphedema, pain, sexual health issues
Targeted therapy	Constipation, cough, diarrhea, fatigue, headache, shortness of breath or trouble breathing, skin reactions

*See Table 1, page 6



Explore the benefits of rehab during survivorship

Rehabilitation care, often referred to as rehab, 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 referred to rehabilitation. In recent years, however, more emphasis has been placed on making rehabilitation services more readily available.

Following are common challenges that may occur during survivorship. If you are having difficulties with any of these or other areas and are not receiving rehabilitation services, ask your doctor how a rehabilitation program may help:

- ▶ Balance issues
- ▶ Climbing stairs
- ▶ Fatigue
- ▶ Limited range of motion
- ▶ Lymphedema
- ▶ Memory or other cognitive difficulties
- ▶ Mobility
- ▶ Pain
- ▶ Personal care, such as showering or getting dressed
- ▶ Problems chewing food
- ▶ Sexual health issues
- ▶ Swallowing difficulty
- ▶ Weakness

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 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, such as when pain occurs, how long it lasts and what triggers it.

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 *Reclaim 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. ■

KEY TAKEAWAYS

- ▶ Late effects can occur months or years after treatment ends.
- ▶ Many factors, such as type of treatment, specific drug and dosage, influence whether you may have late effects.
- ▶ Ask your health care team what to expect and what to do if you have a new symptom.
- ▶ Most late effects can be treated more efficiently if they are caught early, so let your health care team know as soon as a new symptom arises.

Understanding the emotions that accompany survivorship

Taking care of your emotional well-being after treatment ends is just as important as addressing physical effects. Certain feelings may take you by surprise. Instead of being relieved as you might expect, you may be worried, fearful, guilty or depressed. It is important to know that these feelings are completely normal, and there is no magic switch that will make you feel the way you did before your diagnosis. Making a plan for managing these feelings is important for your emotional health.

Family and friends are wonderful sources of support, but they can only understand so much. Find a support group for cancer survivors online or in your area. Opening up to people who have had a similar experience can offer comfort and support that is invaluable. 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.

Contact your doctor about excessive crying or continued feelings of hopelessness or despair. Get immediate medical attention for thoughts of suicide or death. You'll have ups and downs that may be unpredictable, but you don't have to go through them alone.

Below are some of the common emotions you may have.

Anxiety about your future can begin at any time 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, 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. Don't avoid talking to your doctor about it because you think depression is just part of having cancer. It should be treated. It

is extremely important to talk with your doctor about feeling hopeless, helpless or numb. 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.

Emotional insecurity about physical changes can affect your self-esteem and body image. Although physical health is the priority realistically, your emotional well-being may suffer when you don't feel good about yourself. For example, even if you are completely confident in your decision to have a mastectomy, you may feel deep loss once your breasts are gone. Treatments may leave scars, discoloration of the skin, hair loss and lymphedema, which can all affect mood and self-image. Or, you may have sexual side effects from treatment that have affected your performance or feelings of desirability.

Fear about a recurrence or secondary cancer because you are no longer in active treatment is common. 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 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.

Stress is common for you to feel 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. PTS may be treated with medicines (anti-anxiety drugs or antidepressants), relaxation training, support groups or cognitive behavioral therapy. ■

Recognizing and managing scanxiety

Follow-up appointments may cause you to feel anxious or tense. This is known as scanxiety and can apply to any of the imaging scans, laboratory tests or exams you have as part of your follow-up plan. These feelings are understandable because the results will indicate whether your treatment is working the way it is intended. You may begin to feel anxious as the appointment nears and stay that way until you get your results. That is a lot of stress to put on your mind and your body, and it may help to find ways to manage it.

- Set expectations with your doctor or nurse about when and how you will receive the results so you are not left waiting and wondering.
- Remind yourself that it is normal to feel this way. Consider discussing your fears with your friends, a support group or a therapist.
- Keep your mind occupied with things you enjoy, such as reading, playing games or gardening. Staying busy gives you less time to worry.
- Try to calm your nerves with meditation, yoga or deep breathing.



Support and financial resources available for you

CANCER EDUCATION

Advocacy Connector.....	www.advocacyconnector.com
Alex's Lemonade Stand Foundation for Childhood Cancer	www.alexlemonade.org
American Cancer Society.....	www.cancer.org
American Society of Clinical Oncology.....	www.cancer.net
CANCER101.....	www.cancer101.org
CancerCare.....	www.cancer.org
CancerQuest.....	www.cancerquest.org
Cancer Support Community.....	www.cancersupportcommunity.org
Centers for Disease Control and Prevention (CDC).....	www.cdc.gov
The Gathering Place.....	www.touchedbycancer.org
Get Palliative Care.....	www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE).....	www.cancergrace.org
Livestrong Foundation.....	www.livestrong.org
National Cancer Institute.....	www.cancer.gov
National Comprehensive Cancer Network (NCCN).....	www.nccn.org
NCI Cancer Information Service.....	800-422-6237
OncoLink.....	www.oncolink.org
Pine Street Foundation.....	www.pinestreeffoundation.org
Scott Hamilton CARES Foundation.....	www.scottcares.org
Triage Cancer.....	www.triagecancer.org
Union for International Cancer Control.....	www.uicc.org
U.S. National Library of Medicine.....	www.nlm.nih.gov

CAREGIVERS & SUPPORT

4th Angel Patient & Caregiver Mentoring Program.....	www.4thangel.org
Advocacy Connector.....	www.advocacyconnector.com
CanCare.....	www.cancare.org
CANCER101.....	www.cancer101.org, 646-638-2202
Cancer and Careers.....	www.cancerandcareers.org, 646-929-8032
CancerCare.....	www.cancer.org, 800-813-4673
Cancer Connection.....	www.cancer-connection.org, 413-586-1642
Cancer Hope Network.....	www.cancerhopenetwork.org, 877-467-3638
Cancer Really Sucks!.....	www.cancerrealsucks.org
Cancer Support Community.....	www.cancersupportcommunity.org
Cancer Support Community Helpline.....	888-793-9355
Cancer Survivors Network.....	csn.cancer.org, 800-227-2345
Caregiver Action Network.....	www.caregiveraction.org, 855-227-3640
CaringBridge.....	www.caringbridge.org
Center to Advance Palliative Care.....	www.capc.org, 347-835-0658
Chemo Angels.....	www.chemoangels.com
The Children's Treehouse Foundation.....	www.childrenstreehousefdn.org
Cleaning for a Reason.....	www.cleaningforareason.org
Connect Thru Cancer.....	www.connectthrucancer.org
Cooking with Cancer.....	www.cookingwithcancer.org, 205-978-3570
Family Caregiver Alliance.....	www.caregiver.org, 800-445-8106
Friend for Life Cancer Support Network.....	www.friend4life.org
The Gathering Place.....	www.touchedbycancer.org
Guide Posts of Strength, Inc.....	www.cancergps.org, 336-883-4483
Imerman Angels.....	www.imermanangels.org, 866-463-7626
Lacuna Loft.....	www.lacunaloft.org
The LGBT Cancer Project – Out With Cancer.....	www.lgbtcancer.org, 212-673-4920
LivingWell Cancer Resource Center.....	www.livingwellcrc.org, 630-933-7860
Lotsa Helping Hands.....	www.lotsahelpinghands.com
The Lydia Project.....	www.thelydiaproject.org, 877-593-4212
MyLifeLine.....	www.mylifeline.org
Patient Empowerment Network.....	www.powerfulpatients.org
SHARE Caregiver Circle.....	www.sharecancersupport.org/caregivers-support, 844-275-7427
Stronghold Ministry.....	www.mystronghold.org, 877-230-7674
Well Spouse Association.....	www.wellspouse.org, 732-577-8899
weSPARK Cancer Support Center.....	www.wespark.org, 818-906-3022
Wigs & Wishes.....	www.wigsandwishes.org
Your Cancer Story.....	www.yourcancerstory.com

COMPLEMENTARY PROGRAMS & ALTERNATIVE MEDICINE

Believe Big.....	www.believebig.org
The Center for Mind-Body Medicine.....	www.cmbm.org
National Center for Complementary and Integrative Health.....	www.nccih.nih.gov
Office of Cancer Complementary and Alternative Medicine.....	cam.cancer.gov

Society for Oncology Massage.....	www.s4om.org
Stewart's Caring Place.....	www.stewartscaringplace.org
Touch, Caring and Cancer.....	www.partnersinhealing.net

ETHNIC & RELIGIOUS

American Cancer Society Asian and Pacific Islander Cancer Education Materials.....	www.cancer.org/apicem
Asian & Pacific Islander American Health Forum.....	www.apiahf.org
Black Health Care Coalition.....	www.bhccck.org
Catholic Charities USA.....	www.catholiccharitiesusa.org
Indian American Cancer Network.....	www.iacannetwork.org
The Intercultural Cancer Council.....	www.interculturalcancercouncil.org
Latinas Contra Cancer.....	www.latinasconracancer.org
Network of Jewish Human Services Agencies.....	www.ajfca.org
Nueva Vida, Support Network for Latinas With Cancer.....	www.nueva-vida.org
Office of Minority Health.....	www.minorityhealth.hhs.gov
Sharsheret.....	www.sharsheret.org

MENTAL HEALTH SERVICES

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

American Cancer Society.....	www.cancer.org, 800-227-2345
CancerCare.....	www.cancer.org, 800-813-4673
Cancer Support Community.....	www.cancersupportcommunity.org, 888-793-9355
The Leukemia & Lymphoma Society's PearlPoint Nutrition Services.....	www.pearlpoint.org
OncoLink.....	www.oncolink.org

PAIN MANAGEMENT

American Chronic Pain Association.....	www.theacpa.org
American Society of Anesthesiologists.....	www.asahq.org
Cancer Pain Research Consortium.....	www.cancerpainresearch.com
U.S. Pain Foundation.....	www.uspainfoundation.org

SURVIVORSHIP

13thirty Cancer Connect.....	www.13thirty.org
A Time to Heal.....	www.atimetohelfoundation.org
American Childhood Cancer Organization.....	www.acco.org
American Society of Clinical Oncology (ASCO).....	www.cancer.net/survivorship
Angel On My Shoulder.....	www.angelonmysoulder.org
Cancer ABCs.....	www.cancerabcs.org
Cancer and Careers.....	www.cancerandcareers.org
Cancer Hope Network.....	www.cancerhopenetwork.org
Cancer Support Community.....	www.cancersupportcommunity.org
Cancer Survivors' Fund.....	www.cancersurvivorsfund.org
Cancer Survivors Network (Online Community).....	www.csn.cancer.org
CancerCare.....	www.cancer.org
Catherine Boulay Foundation.....	www.catherineboulayfoundation.org
Centers for Disease Control and Prevention (CDC).....	www.cdc.gov/cancer/survivors
Children's Cancer Research Fund.....	www.childrenscancer.org
Global Resource for Advancing Cancer Education (GRACE).....	www.cancergrace.org
Hope for Two... The Pregnant with Cancer Network.....	www.hopefortwo.org
Imerman Angels.....	www.imermanangels.org
Indian American Cancer Network.....	www.iacannetwork.org
Lacuna Loft.....	www.lacunaloft.org
Law Enforcement Cancer Support Foundation.....	www.lawenforcementcancer.org
National Cancer Survivors Day.....	www.ncsd.org
The National Children's Cancer Society.....	www.thenccs.org
National Coalition for Cancer Survivorship.....	www.canceradvocacy.org
National LGBT Cancer Network.....	www.cancer-network.org
National LGBT Cancer Project.....	www.lgbtcancer.org
Reel Recovery.....	www.reelrecovery.org
River Discovery.....	www.riverdiscovery.org
Stupid Cancer.....	www.stupidcancer.org
Survivor's Outdoor Experience.....	www.survivorsoutdoorexperience.org
Triage Cancer.....	www.triagecancer.org
True North Treks.....	www.truenorthtreks.org
Walk with Sally.....	www.walkwithsally.org

➔ For more resources, go to PatientResource.com

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