You’re stronger than you know.

GENNY, 49, COLORECTAL CANCER SURVIVOR, LIVESTRONG AT THE YMCA PARTICIPANT

LIVESTRONG at the YMCA promotes the importance of physical activity after a cancer diagnosis. This 12-week program is designed to empower survivors and improve their muscle mass, strength, energy levels and quality of life. It’s available at more than 400 YMCA locations and is offered at little to no cost to the participant. Find a program near you today.

Learn more at LIVESTRONG.org/YMCA
Transitioning into a post-treatment schedule

As a survivor, you’ve battled the disease, the treatments and the side effects, now joining an elite “club” as many survivors call it. You and millions of others in the United States have lived with, through and beyond cancer. Although being a member means you’ve likely gone through one of the most difficult challenges in your life, you’re now an integral part of a network composed of strong individuals who understand and appreciate the need for support and camaraderie, perhaps now more than ever.

As you transition into survivorship, you may experience some unexpected difficulty. You may begin to realize that unfortunately the issues related to your cancer do not end when treatment stops. Your history of disease will affect both your health care needs and your lifestyle every day from here on. Knowing what to expect, the resources available and how other survivors have been able to handle the changes can be valuable assets as you continue your own journey into life after cancer.

DEFINING CANCER SURVIVORSHIP
Cancer survivorship is often defined in two ways: completing treatment and having no remaining signs of disease; or living with, through and beyond cancer. According to the second definition, survivorship begins at diagnosis, continues through treatment and persists past it—including those who are living disease-free and those who are managing cancer as a chronic condition. For the purpose of this guide, we’ll use the terms “survivor” and “survivorship” to refer to any individual who has moved past initial treatment and is readjusting to daily life.

SURVIVORSHIP STATISTICS
Early screening tests, new developments and improvements in treatment, and better side effect management are all credited with the increasing cancer survival rates. More than 60 percent of the estimated 14.5 million survivors in the U.S. today are five or more years beyond their original diagnoses, with 15 percent of individuals diagnosed 20 or more years ago.

The cancer community is realizing now that with more and more survivors comes the responsibility to continue care beyond treatment. Recovery – both physical and mental – takes time, resources, education, commitment and patience. Many national advocacy groups are addressing these issues by creating survivorship plans in an effort to ease the transition for both patients and health care providers.

WHAT TO EXPECT
Cancer and its treatment can affect your body long after it ends—for days, months or even years. Many cancer survivors must manage continuing and late effects of treatment, such as infertility, chronic pain or cognitive changes. There are ways to alleviate and manage these effects, so maintaining an open dialogue with your health care team even after treatment has ended is vital. Your quality of life after cancer should be a continuing, lifelong focus as you move forward from your diagnosis.

The effects of cancer and its treatments also include psychosocial and emotional changes. Surviving cancer can stir up a lot of feelings, which will be different for everyone. Survivors often experience a mixture of emotions, from relief and joy to stress, depression, guilt or fear. It’s important to be aware that these emotions and many others may arise so you can be prepared to acknowledge, accept and move past them—and seek the appropriate help if you have trouble doing so.

ABOUT THIS GUIDE
While this publication is primarily for people who have survived a cancer diagnosis, family and friends of survivors can also gain insight and knowledge that will help them provide support to their loved ones. Published in partnership with the LIVESTRONG Foundation, this guide provides information about creating a survivorship plan, re-entering the work force, managing the late effects of cancer, living a healthy lifestyle, coping with the emotional effects of cancer, reclaiming your sexuality, resuming your family life and more. You will also find information about financial considerations, support and advocacy groups and throughout the guide you will be directed to additional websites to help you better understand cancer survivorship.

BY THE NUMBERS
64% of cancer survivors were diagnosed five or more years ago, and 15% were diagnosed 20 or more years ago.
and then keep it
One Day at a Time

I promised my mentor on his deathbed that I would help others just like he helped me, and I’ve been assembling an army of cancer warriors ever since.

When I was first diagnosed, I asked my doctor what the chances were of living five years. He said 2 percent—and I was ecstatic! I said, “You just saved my life; I didn’t think I had any!”

I’ve since been through two separate recurrences, three surgeries and three years of chemotherapy, but I’m still here! Over the years, I’ve watched my son graduate and get married, and now my wife and I have four grandsons and a granddaughter.

I always advise other cancer patients that it’s all about setting goals and keeping promises, along with paying attention to three very important F words:

1. **Faith** — Because I had faith, I did not seek a second opinion and didn’t read one word on the Internet about cancer. I just found the best team of doctors possible and had faith in their abilities to handle my disease. I figure you only get one chance at survival, so get the right team on the field and play to win.

2. **Family** — You’re going to need support, so get rid of negative people, even if it’s your mom. Cancer is negative enough and you’ll want to surround yourself with positive people. For me, that was my family, and I wouldn’t be here without them.

3. **Facilities** — Having a team of doctors with experience treating your type of cancer is crucial, as is finding a facility with state-of-the-art equipment and cutting-edge technology. You’re going to need confidence to get through this, and if you don’t have it, keep looking until you find it. Don’t worry about hurting anyone’s feelings; this is your life, and you only have one chance to live.

There’s a lot to learn about life that I believe only God and cancer can teach you. However, cancer knows cancer, which is why I feel that having a mentor (and being one to others) is an absolute must.

This damn disease cost me my career and a lot of money, but it gave me a new job as an advocate and author. I can’t spell, but I had a story to tell, and I promised I would help others get through this just like my friend helped me.

When I decided to write a book and asked my editor for advice on how to get started, he said, “Just put your ass in a chair and type.” So that’s what I did!

I speak with fellow cancer warriors from all around the country who have read my book and are appreciative for all of the information I include. One woman was upset because she started my book one night and couldn’t put it down until she finished it at 3 a.m.!

“To See Another Sunrise … How to Overcome Anything One Day at a Time” is full of lessons I’ve learned that can hopefully help cancer patients and their families cherish the good days and get through the bad ones—one day at a time.
Creating a survivorship plan

Now that you’re past primary treatment, your work is not done. Similar to the way your treatment plan helped you navigate treatment, a survivorship plan can be a valuable tool to help you enjoy a healthier future.

Think of your survivorship plan as a life wellness plan—a roadmap that helps you figure out where you’re going and how to get there. No single plan applies to every patient, but certain aspects of a plan may be similar. Your survivorship plan should include everything from comprehensive information about the treatments you received to a follow-up care schedule and more.

Here you’ll find information that describes each element of a survivorship plan and its associated parts. While you may be able to compile most of this information on your own, be sure to thoroughly discuss each component of your survivorship plan with your medical team.

MEDICAL HISTORY
A well-documented medical history record can help any doctors you see in the future provide you with the best possible care. Your records should contain your entire history of medical care – including symptoms, tests, procedures, treatments, dates and side effects – from as far back as you can accurately remember or track down. Include information about vaccines and immunizations; dental issues; prescription and over-the-counter medicines you have taken in the recent past or are currently taking; allergies and sensitivities; past injuries; nutritional habits; pain problems; and ongoing health problems.

It’s also important to include information about your family’s medical history, including any history of cancer. Ideally, you’ll be able to gather information from multiple generations of family members, from both sides of your family. Certain types of cancer, such as breast, colon, pancreatic, melanoma, ovarian and prostate have a hereditary link, which means they may be more common in some families than others. This might be because family members share certain risk factors, such as smoking or obesity, or because the cancer is caused by an abnormal gene being passed from parents to their children (inherited cancer).

If cancer is prevalent in your family, your doctor may recommend genetic counseling, potentially followed by testing to look for gene mutations (changes). Certain mutations can indicate an increased risk for developing certain diseases. The presence of a mutation does not guarantee you will develop cancer, and only about 5 to 10 percent of all cancers are inherited. However, knowing whether a mutation exists can help you and your doctor develop a plan to reduce your risk and keep you healthy.

If you do not yet have your family’s medical history written down, reach out to your relatives as soon as possible to start compiling a record. It will not only benefit you and your health, it can also help your family members.

DIAGNOSIS
Your survivorship plan should accurately reflect your exact cancer diagnosis, including the date of diagnosis, specific cancer type, stage and grade of the cancer, location of the cancer, and your hormonal status and biomarkers (if applicable). If you sought a second or third opinion and if any of these details differed – or if anything changed during the course of your treatment – that information should be documented as well.

HEALTH CARE TEAM
If you haven’t already, create a contact log for your entire health care team. List names, titles, phone numbers and addresses; also describe the role each person played (or plays) in your care. This way, if you or one of your future providers ever has a question about a past treatment or interaction, you will know exactly whom to contact for clarification.

TREATMENT
Including a summary of your cancer treatment in your survivorship plan can help ensure you get the best possible health care in the future. Ideally, you already have written records of all your treatments. However, if you were unable to gather this information, ask your medical team to help you create a treatment plan summary. Your team may include your doctor, nurse, social worker and/or physician assistant. Many cancer centers have electronic patient records that allow patient access to their own online medical record information. If this is the case, it may be easiest to print out your medical record information, focusing on the items listed below. Include all of the following details applicable to your treatment:

- **Diagnostic tests**: descriptions, dates and results
- **Hospital stays**: reasons, dates, medications administered and/or procedures performed
- **Surgeries**: types, dates and recovery times
- **Radiation therapies**: sites, dates and total amount of radiation
- **Chemotherapy and/or other drug treatments**: drug names, dosages and types, as well as administration dates and duration
- **Palliative care**: specifics about any symptom management remedies you received (e.g., antiemetic medication to combat nausea)

QUESTIONS TO ASK YOUR MEDICAL TEAM TO HELP YOU COMPILE YOUR SURVIVORSHIP PLAN

- What follow-up care plan would you recommend? How often should I schedule follow-up visits?
- What signs or symptoms will show if my cancer returns? (What signs or symptoms should I watch for?)
- Should I see a cancer rehabilitation therapist to help me overcome my lingering side effects such as fatigue, peripheral neuropathy, and other physical symptoms?
- What are the long-term or late-term side effects I should expect from treatment?
- How can I obtain a treatment summary and survivorship care plan for my records?
- Which health care provider is in charge of my follow-up care?
- What survivorship support services are available to me and my family?
- Can you suggest a counselor or support group to help me (or my family) adjust to survivorship?
**Other services:** specifics about other services you received (e.g., cancer rehabilitation, genetics evaluation, fertility preservation, advice from a dietitian, counseling, etc.)

Be sure to also include details about your responses and reactions to treatment(s) as well as any complications and/or side effects they caused.

**RISK FOR LATE EFFECTS, RECURRENCE AND/OR SECOND CANCERS**

As you now know, cancer and its treatment can result in several different side effects—before, during and after treatment. Late effects are those that develop weeks, months or even years after your treatment ends. Because of this, your survivorship plan should include information about your risk for developing certain late effects based on your specific type of cancer and treatment plan. Be sure to ask your doctor about the signs and symptoms you should watch for so that you can detect and manage them before they become serious. See page 10 for more information about managing late effects.

Your survivorship plan should also discuss the risk that your cancer may come back as a local recurrence (where it originally developed) or as a distant recurrence in the form of metastatic disease, as well as your risk for developing a new type of cancer (second cancer). It's important to be aware of these possibilities so you can monitor your health and identify any new signs of cancer as early as possible. See page 16 for more information on monitoring for recurrence and second cancers.

**FOLLOW-UP CARE SCHEDULE**

At the end of your treatment plan, your doctor should provide you with a follow-up care schedule. This schedule will detail the information regarding future appointments, diagnostic tests and exams. Ask about how often you will have checkups for the first year, second year, etc. Also record any medications you’ll be taking, including maintenance therapy drugs. Record details about the regimen, such as dosage and timing, location (if you need to receive therapy under the supervision of a medical professional) and the expected duration of treatment. And ask about what side effects to monitor for while on maintenance therapy. You should also ask about which physicians from your care team, if any, will be monitoring your follow-up care. If your doctor does not offer this information, ask for it and make a copy for your survivorship plan. It then becomes your responsibility to precisely adhere to this follow-up schedule.

**HEALTHY LIVING**

Staying healthy and active is perhaps as important as sticking to your follow-up schedule. While there are some general nutrition guidelines everyone can follow, what is considered healthy eating may be slightly different for every survivor. Talk to your doctor or ask for a referral to a dietitian to determine the healthiest eating habits for you. Also, ask about an exercise regimen that you can follow. Unless you continued to exercise throughout treatment, you’ll likely need to start slowly and gradually build up your strength and endurance. Ask your doctor or a trained professional to outline an exercise plan to help get you started and if you would benefit from meeting with a cancer rehabilitation therapist or joining a group exercise program.

In addition, you and your doctor may choose to add other healthy goals and recommendations to your survivorship plan. For example, if you smoke, you might consider attending local smoking cessation programs. Other healthy additions to your survivorship plan include setting a limit on your monthly alcohol consumption, swearing to wear sunscreen every time you go outside and listing strategies to help prevent osteoporosis. Also consider writing down your life goals. By setting life goals such as starting a family, working toward a promotion or taking a celebratory vacation, maintaining a healthy lifestyle will become even more impactful as you work toward achieving those goals. See page 18 for more information on staying healthy and active.

**ESTATE PLANNING**

In your survivorship plan, you might also want to include your estate plan. This usually involves completing an advance directive, naming a power of attorney, developing a will and possibly establishing trusts.

- An advance directive, known as a “living will,” provides your doctor with information regarding what types of life-sustaining treatment you want and helps ensure you receive the level of care you desire.
- A power of attorney is someone who has the authority to handle your financial affairs if you’re unable to do so yourself for any period of time.
- A will allows you to state how you would like to distribute your assets.
- With a trust, you can specify the conditions under which your designated beneficiaries receive those assets.

While estate planning is a task that many people prefer to avoid, it can bring peace of mind and a sense of security for you as well as for your family. Every adult should consider estate planning, including people who have never had cancer.

**RESOURCES**

It can also be beneficial to use your survivorship plan as a resource tool. Compile an at-a-glance list of resources on a variety of topics, such as nonprofit cancer services, employment rights, insurance information, emotional support services, financial assistance and more. Creating a comprehensive list now may pay off down the road if you suddenly find yourself needing assistance.

**ADHERENCE**

Your survivorship plan is only useful if you actually understand and use it. If you have questions about any of the elements in your plan, don’t hesitate to ask your doctor. Also, continue to update your plan as necessary and make several copies of it. This will allow you to keep one out in the open for constant reference, store one in a safe place with your other important documents, and give one to the doctors you see in the future.

**ADDITIONAL RESOURCES**

- **American Cancer Society:** [www.cancer.org](http://www.cancer.org)
- **Survivorship Care Plans**
- **LIVESTRONG:** [www.livestrong.org](http://www.livestrong.org)
- **LIVESTRONG at the YMCA**
- **LIVESTRONG Care Plan:** [www.livestrongcareplan.org](http://www.livestrongcareplan.org)
- **National Coalition for Cancer Survivorship:** [www.canceradvocacy.org](http://www.canceradvocacy.org)
- **Living Beyond Cancer**
Managing ongoing financial and insurance challenges

Cancer not only impacts your body and mind—it also can do a number on your financial well-being. Some healthcare professionals actually refer to financial challenges associated with cancer treatment as a side effect, referred to as financial toxicity. Even individuals with insurance coverage may have difficulty affording treatments and other cancer-related costs, which can include direct medical costs, non-medical costs (such as transportation or child care) and daily living expenses, that can become a burden during treatment and into survivorship. And it seems like many insurance companies continue to increase deductibles and co-payments. Fortunately, organizations and resources are available that can provide help with managing your finances and finding financial assistance opportunities. See page 24 for a list of financial resources.

WORK WITH PEOPLE WHO CAN HELP
Many people can help you handle insurance matters. Doctors’ offices typically have a billing person; the cancer care team usually includes a social worker; and most medical facilities have financial counselors and patient navigators on staff. If you can, try to work with the same person for your financial help.

MAINTAINING HEALTH INSURANCE
It’s important for cancer survivors to maintain adequate and dependable health insurance even after cancer treatment ends. There may be medical concerns to consider, such as recurrence (cancer returning), a second cancer (development of another type of cancer, different than the original diagnosis) or chronic conditions. Side effects that last beyond treatment or develop long after, known as late effects, may also be a concern. In addition to regular follow-ups, your primary care physician may refer you to certain specialists for the best continued care after cancer. For these reasons, it’s important to know all of your options.

DECODING THE AFFORDABLE CARE ACT
The Patient Protection and Affordable Care Act of 2010 is also known as the Affordable Care Act. This law changed many rules about health insurance coverage in the U.S., making health care more accessible and more affordable for many.

ACCESSIBILITY
Some key components of the law related to access to care include the following:
• The act enables adult children to stay on a parent’s plan until their 26th birthday.
• Health insurance companies cannot deny coverage for a pre-existing condition.
• Health insurance plans cannot stop coverage when a person becomes sick.
• Enhanced preventive benefits and screenings are available at no cost for all insured parties.
• The act creates a formalized list of “essential health benefits” that ensures all insurance policies provide minimum coverage for services within 10 categories of care.
• The act removes annual and lifetime limits on essential health benefit services, which is particularly helpful for cancer patients.
• It creates “Marketplaces” that help consumers find and enroll in affordable health coverage.
• The law improves coverage for patients participating in clinical trials.

QUALITY OF CARE
The Affordable Care Act improves the quality of care for all people, especially with regard to the prevention and treatment of cancer. First, the law mandates that health insurers eliminate copays for certain preventive health services including colorectal cancer screening for adults older than 50, mammograms every one to two years for women older than 40, or regular Pap testing. In addition, all new health insurance plans must include coverage of cancer treatment, including treatment focused on pain management and other quality-of-life issues and follow-up care. Lastly, the law ensures that the majority of costs of participating in a clinical trial will be covered.

HEALTH INSURANCE MARKETPLACES
Each of the 50 states and the District of Columbia now offer residents a central online hub to find and secure health insurance in their region. These websites allow users to compare available plans and enroll directly in a plan that meets their needs. Navigators and application counselors are available in each state to help patients make informed decisions during the selection process. For a full list of each state’s Marketplace contact information, visit www.healthcare.gov. Open enrollment for insurance plans through the Marketplace will be during the fall for plans that take effect January 1.

The Affordable Care Act is a complex law and includes many features beyond what is described here. Visit www.healthcare.gov to learn what the law means to you. The site includes contact information for consumer assistance programs in each state, where you can get answers to specific questions.

FINDING INSURANCE
Health insurance for many Americans is sponsored by an employer, and employees are asked to pay a portion of the premium to maintain coverage. There is a wide range of coverage options available, and the coverage and compensation associated with employer health care benefits differ for each employer.

Individuals age 65 or older or individuals with a qualifying disability may be eligible for Medicare, a federal government insurance program. Individuals or families who are considered low-income may be eligible for Medicaid, another federal government insurance program. Additional coverage options may be available through military programs like TRICARE, the Department of Defense Healthcare program and the Department of Veterans Affairs.

Purchasing individual health care is also an option, which can be done through the Health Insurance Marketplace established by the Affordable Care Act. This marketplace allows people to compare and select an affordable health insurance plan to meet their needs. Visit www.healthcare.gov for additional information on the Health Insurance Marketplace.

Be sure to verify any new information each year before selecting or changing from one insurance plan to another to make sure you understand any changes in coverage. Even if you are re-enrolling in the same plan, it is smart to review your policy, as some components of your plan may change from year to year.
Even though you are finished with your primary cancer treatment, you can still contribute to cancer research and help others facing a new diagnosis. Did you know that nearly all of the cancer-fighting drugs and treatment methods currently available exist only because they were thoroughly tested beforehand? These tests, known as clinical trials, are research studies designed to evaluate the safety and effectiveness of new drugs or other types of therapies. Many of these trials have led to remarkable advancements in cancer care and research, and they are only possible because of volunteers who agreed to participate.

**TYPES OF CANCER CLINICAL TRIALS**

Five types of cancer clinical trials exist. Treatment trials are specifically for individuals who have cancer, and they evaluate whether a new treatment (e.g., drug, surgery, radiation therapy) or new combination of treatments is better than the current standard of care. Quality-of-life trials, which are clinical trials for supportive and palliative care, study ways to improve the quality of life for cancer patients and survivors. These studies focus on people experiencing symptoms associated with cancer and cancer treatment. These trials may also study the effects of nutrition, group therapy, counseling and other therapies that may help cancer patients and survivors.

The other three types of clinical trials – prevention, screening and diagnostic – evaluate tests that may help cancer patients and survivors. These studies focus on people experiencing symptoms associated with cancer and cancer treatment. These trials may also study the effects of nutrition, group therapy, counseling and other therapies that may help cancer patients and survivors.

**HOW TO FIND A CLINICAL TRIAL**

To find a clinical trial, you can use resources like the National Cancer Institute (NCI) or the National Institutes of Health (NIH). The NCI offers a searchable list of more than 12,000 active clinical research trials, and the NIH runs a clinical trial registry and the largest clinical trials database available. You can search studies using several criteria, such as cancer type or condition, specific location, treatment types or simply by using keywords. Just be sure to verify the information is up-to-date before proceeding. You can also talk to your doctor about clinical trials in your area.

**QUALIFYING FOR A CLINICAL TRIAL**

All clinical trials have a protocol (description of what is being done, how and why) and eligibility requirements (factors that determine whether you qualify to participate in that specific trial). It’s likely that you will undergo medical testing to determine whether you meet all the requirements before you find out if you are accepted. The eligibility criteria of a study help researchers eliminate factors that may alter the purpose or focus of a study. Once accepted for the study, a participant may opt out at any time for any reason.

**COVERING THE COST OF A CLINICAL TRIAL**

Costs associated with a clinical trial fall into two categories: patient care costs and research costs. Patient care costs are related to your treatment outside of the study, such as going to the doctor, any stays in the hospital or certain testing procedures (lab tests, imaging tests). Under the Affordable Care Act, these costs are now covered by insurance in almost all cases. Research costs are those directly related to the study, such as the study drug, testing performed for research purposes, or additional doctor visits. It’s common for the trial sponsor to cover these costs but not guaranteed, and insurance does not typically cover research costs. It’s important to talk to your insurance provider before taking part in a clinical trial. Visit www.healthcare.gov to learn more.

**WHAT TO EXPECT IF YOU PARTICIPATE IN A CLINICAL TRIAL**

The research team will give you specific instructions, evaluate your health at the beginning of the trial, monitor it carefully during the trial and stay in touch after it ends. To receive the greatest benefit, you should carefully follow the instructions provided and remain in contact with the research staff. Trials are usually conducted in a hospital, doctor’s office or community clinic.

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**CLINICAL TRIALS: MYTH vs FACT**

[**MYTH**] Clinical trials are not safe.
[**MYTH**] Clinical trials have many built-in safeguards to ensure that participants’ rights and safety are protected. These safeguards include an institutional review board, data and safety monitoring board, and an ongoing informed consent process.

[**MYTH**] The cost of care in a clinical trial is not covered by health insurance.
[**FACT**] Under the new health care laws, patient care costs (such as going to the doctor, any stays in the hospital or certain testing procedures) are covered by insurance. Research costs are those directly related to the study. It’s common for the trial sponsor to cover these costs but not guaranteed, and insurance does not typically cover research costs.

[**MYTH**] Clinical trials only take place at large hospitals or cancer centers.
[**FACT**] Many clinical trials are now done at local hospitals, cancer centers and doctors’ offices.

[**MYTH**] A clinical trial must be recommended by a doctor in order for a person to participate.

[**FACT**] If your doctor does not talk to you about clinical trials, raise the topic yourself. You can also search for clinical trials online; contact information for trials is given.

[**MYTH**] Participating in clinical trials are treated like “guinea pigs.”

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**FACT** The overwhelming majority of clinical trial participants (97 percent) say they were treated with dignity and respect; 93 percent report having a positive experience in the trial.
More than three million of today’s cancer survivors are still of working age. If you took time off during cancer treatment, re-entering the work force can be a difficult transition, whether you are returning full time, part time or starting a new job. For some people, going back to work is a welcome return to normalcy. For others, it’s a source of great anxiety, yet a financial necessity. And for others still, it’s a confusing clutter of feelings.

Mixed emotions are normal, so give yourself plenty of time to work through them. Setting career goals, understanding disclosure obligations and determining any necessary modifications you’ll need can all help you clear your head and ease the transition.

GOALS
Cancer is a life-altering event that affects many aspects of your life. Before you go back to work, it’s important to re-evaluate your career goals. Do you still want the same things you were working toward before your diagnosis, or have your priorities shifted in some way? It’s important to share your goals and priorities with your friends and family; they can help you clarify your new priorities as they apply to your career.

It’s also important to re-examine your career abilities. Talk to your doctor about what impact your follow-up treatment schedule and long-term side effects might have on your work performance. Depending on the conclusions you reach in that conversation, you may decide you want to first try part-time work to ease back into the routine, or you may need to change course and pursue a career that’s less physically or emotionally demanding.

EXPECTATIONS
In addition to reflecting on your career goals and abilities, it’s important to manage your expectations. It’s unrealistic to assume that everything will be exactly the same as it was before your diagnosis. Before you return to the office, think about all of the possible scenarios you might encounter. For example, brainstorm ways to get up to speed on everything that happened in your absence. Perhaps you can attend a training session or review recent projects. Also run through possible reactions from your co-workers. Some may keep their distance and act awkwardly, while others may ask you direct personal questions. Try to anticipate what you may encounter so you’re prepared for your first day back.

DISCLOSURE
The Americans with Disabilities Act (ADA) prohibits current and future employers from asking about your medical history. In other words, you aren’t obligated to tell anyone about your cancer, so it’s completely up to you how much you want to disclose. In some cases, however, it may be necessary for you to talk to your employer. For instance, if you’ll require reasonable accommodations such as a flexible schedule or modified equipment, your employer is only required to comply if he or she knows about your condition. (See sidebar for more information about the ADA.) Disclosure preferences vary among survivors based on their needs, their desire for privacy and their comfort level with their colleagues. Only you know what’s right for you.

MODIFICATIONS
Even into survivorship, you may still be dealing with some difficult side effects. You might require temporary adjustments at work, such as a flexible schedule, reduced hours, a redesigned workstation, the option to work from home and/or altered responsibilities. While your employer is required under the ADA to provide reasonable accommodations, it’s important to not take advantage of that fact and to be as fair and upfront with him or her as possible.

Depending on your job, it might be a good idea to talk to your supervisor about your workload and be as realistic as possible about what you can manage. Work together to delegate what may not be possible and to prioritize what’s left. Prioritization will help you work on and finish the most pressing projects first, in case you need to step out for an appointment or to rest.

Speaking of rest, you may now find that lingering fatigue zaps your energy more quickly than it used to. If this is the case, track your energy levels at different times of
MANAGING YOUR FATIGUE AT WORK
Some cancer survivors experience long-lasting fatigue, even after treatment has ended. It can make people feel too tired to eat or even walk to the bathroom and going to or staying at work can be a difficult task if you experience fatigue. Below are some tips to help manage your fatigue while at work.
- **Take it slow.** Work at a moderate pace to prevent exhaustion. You can also combine motions and activities to avoid using excess energy.
- **Prioritize.** Decide what work is important and what can be delegated. Try to use your energy on the tasks that are most important.
- **Organize your workspace.** Rearrange your most commonly-used items to reduce reaching or searching for them. Instead of using over-the-head storage, keep items lower for easier access.
- **Schedule breaks for rest.** Balance periods of rest and work throughout the day. Short, frequent breaks for rest can be very beneficial, even if you don’t feel fatigued.
- **Practice proper body mechanics.** Make simple changes in your daily activities to avoid fatigue. Sit in a chair with good support, bend at the knees instead of at the back, and take even breaths.
- **Make yourself comfortable.** Wear clothing that allows you to breathe and move easily. You should also try to avoid extreme temperatures and other job conditions that can cause discomfort.
- **Keep your body healthy.** Make sure you are meeting your calorie needs, especially during busy work days. You should drink at least 64 ounces of water each day and consume foods that can help decrease feelings of fatigue such as yogurt, nuts, tea, and mint. Talk to your doctor or dietician about additional nutrition recommendations that are right for you.

COMMUNICATION
Whenever you talk to your supervisor – about either work or your health – do your best to project confidence, competence and reassurance that your workload is under control. As time passes, continue to work hard to maintain clear and constant communication with your co-workers. For example, if you encounter a particularly rough patch, it may be the most beneficial to be upfront about it so your supervisor and colleagues can help keep things on pace. Then, when you bounce back, do what you can to return the favor. In short, the more you communicate and keep an ongoing dialogue rather than having a one-time discussion, the less stressful your work life will likely be.

SUPPORT
Lastly, don’t assume you must handle this transition on your own. Returning to work after cancer is no small feat, so finding a counselor or seeking a support group where you can talk to people in a similar situation is often helpful. Your company’s benefits package may even cover occupational health services. Help is available if you seek it out.

RETURNING TO SCHOOL
After undergoing cancer treatment, returning to school can be concerning. Preparation may help ease anxiety and any feelings of being overwhelmed. Also know that it can be physically and emotionally tiring, and that the transition may need to happen slowly. Try the following tips:
- **Work assignments may need to be completed while you are at home or in the hospital.** Notify the school of expected absences to prevent falling behind.
- **Ask for simple accommodations to help you ease the transition, like having two sets of textbooks so you can keep one set at home.**
- **Look into any academic support offered by hospitals for children staying an extended period of time and struggling to complete assignments.**
- **Maintain open communication throughout and request additional resources from the school, such as emotional and social support, to help transition between school and treatment.**
- **Address learning or classroom difficulties.** Federal law allows students with disabilities to receive special accommodations. Determine what these may be and make the proper arrangements.
- **Consider visiting the school or campus before returning for classes.** It could also be helpful to meet with friends or attend a school-hosted event to be sure you are up to date.
- **If appropriate, meet with an academic advisor to discuss graduation needs and requirements.**

FINDING A NEW JOB AFTER CANCER
Your cancer history shouldn’t affect your ability to get a job, however, you may still need to consider, adjust and/or rehearse a few things before you start sending resumes and going to interviews.

**REFORMAT YOUR RESUME**
If your cancer caused any significant gaps in your resume, you may want to deviate from the standard chronological format in favor of a functional format. Functional resumes highlight job skills and qualifications first, rather than leading with employment history. If your resume includes dates, you may also want to omit the months and include only the years, or you can instead choose to simply list the number of years of service; this allows you to be discreet while still remaining truthful.

**REHEARSE YOUR RESPONSES**
While interviewers legally cannot ask about your medical history, they can ask about gaps in employment. So it’s important to prepare for this question. What you say is up to you, but here is an example: “I took a short time off to deal with a health issue, but it’s now resolved and I’m eager to get back to work.” Then, immediately turn the focus of the conversation back to your strengths.
Managing physical late effects

Certain cancer treatments unfortunately bring an increased risk of side effects that can develop days, months or even years after treatment has ended. These side effects, known as late effects, will vary from person to person, and not all survivors will experience late effects.

It’s important to discuss all of your previous cancer treatments with your doctor so that you know what late effects you’re more likely to experience, any preventive measures you can take and how to best manage them if they do happen.

INFERTILITY AND FERTILITY OPTIONS

The adrenal gland, thyroid, ovaries and testes are all part of the endocrine system, which is responsible for releasing the hormones that control fertility, regulate growth and stimulate puberty. Fertility issues arise when cancer or its treatments damage any part of the endocrine system, including the area of the brain that controls it. Damage to the endocrine system may cause temporary infertility (lasting months or even years) or permanent infertility.

Because chemotherapy and radiation are known to cause damage to reproductive cells, people who underwent these treatments are at a greater risk for infertility, whether temporary or permanent. Higher doses and longer treatments typically result in longer periods of infertility and increased risk of permanent infertility. Surgeries to remove both testicles, both ovaries or the uterus also result in permanent infertility.

It’s possible to discuss fertility options at any point during cancer treatment; however, your best chances of preserving your fertility are prior to beginning treatment. Options such as freezing embryos, eggs and ovarian tissue or sperm banking exist for some cancer patients, and it’s important to discuss these options with your health care team as early as possible in your cancer journey. There are also several organizations available to help with the financial difficulties that many cancer patients face when considering fertility preservation. To fully understand your options at any stage in your cancer journey, including survivorship, talk to your doctor. He or she may refer you to a fertility specialist who will be able to talk to you about the possibility of using donor embryos or eggs, or alternative options like surrogacy or adoption.

For women considering pregnancy, it’s important to understand the possible long-term side effects related to chemotherapy and radiation; the risk for some of these late effects may be increased by pregnancy. Effects such as damage to your organs (especially your heart and lungs) should be carefully considered before you try to become pregnant, whether naturally or with reproductive help. Also, because chemotherapy and radiation are known to cause genetic damage to reproductive cells, your doctor will likely suggest a specific waiting period after treatment ends before you try to get pregnant. It’s important to discuss this with your doctor to determine the safest and most effective way to move forward.

CHRONIC PAIN

Chronic pain is pain that lasts long after a bodily injury is healed. Little is known about long-term pain in cancer-free survivors, and not all survivors experience chronic pain. The causes vary from person to person, but some common reasons for cancer-related chronic pain are:

- bone metastasis (occurs when cancer returns and spreads to the bones)
- peripheral neuropathy (a disorder of the nerves outside the brain and spinal cord)
- steroid use during cancer treatment (leading to weakened and painful bones)
- untreated or inadequately treated pain after surgery

While chronic pain can be a serious late effect for some survivors, many options exist to effectively treat it. Mild pain can often be controlled with over-the-counter pain relievers, such as aspirin, acetaminophen (Tylenol, etc.), ibuprofen (Advil, Motrin, etc.) and naproxen (Aleve). More severe pain can be controlled with prescription drugs, such as opioids (narcotics), and neurosurgical approaches, such as electrical stimulation, intrathecal drug delivery (“pain pump” that delivers medication through a catheter into the spinal cord) and nerve blocks. You can also help manage your pain by using some complementary therapies shown to be beneficial, including relaxation therapy, yoga, acupuncture, imagery, biofeedback, physical therapy and counseling.

Cancer pain is sometimes undertreated because many patients are reluctant to discuss it. Pain relief works best when it’s done proactively rather than reactively, and, ideally, pain should be addressed long before it becomes an emergency. Ask about pain management right from the start, and continually alert your doctor at the first sign of significant pain. A pain diary can help you monitor your pain, know what to report and decide when to call your doctor.

Your primary care doctor and your oncology specialist will likely communicate with one another to determine the optimal method for treating your pain. Cancer rehabilitation may be a good option to help minimize chronic pain and keep you physically active. And you may even benefit from a palliative care consultation. Although many people associate palliative care with end of life, this is often not the case. Palliative care is symptom management. Many cancer patients see a palliative care specialist as part of their treatment team. This can be beneficial not only to manage treatment side effects but also any long-term effects, such as cancer pain, that you experience into survivorship.

Also, be sure to involve those close to you. Family and friends can provide emotional support and physically help you on days when you’re experiencing cancer-related pain.

COGNITIVE DYSFUNCTION

Cognitive dysfunction, sometimes referred to as “chemo-brain,” is often described as being unable to recall details, names or dates clearly; having memory lapses in the middle of conversations; difficulty paying attention; and a general “mental fog.” Research has shown that cognitive dysfunction related to cancer treatment is real, affecting attention, concentration, short-term memory, language skills, organizational ability and arithmetic skills. Cognitive dysfunction may have occurred during your cancer treatment but may also occur months or even years after treatment ends and can result from treatments other than chemotherapy.

Treatment options are available for cogni-
tive dysfunction that continues after treatment or begins years later. A drug commonly used to treat Alzheimer’s disease, donepezil hydrochloride (Aricept), and some stimulant drugs such as methylphenidate (Ritalin) have been effective in some people with cognitive dysfunction. Additional options include occupational therapy (which may be available through a cancer rehabilitation program), vocational rehabilitation to improve skills needed for daily living and job performance, and cognitive rehabilitation and training to help improve cognitive skills and learn ways to cope with cognitive deficits.

It’s important to talk to your doctor when you first notice signs of cognitive dysfunction. To determine how best to handle your symptoms, your doctor will evaluate you to see if the cause is something other than cancer treatment and may prescribe medication or rehabilitation if necessary.

### Fatigue and Sleep Disorders

Fatigue, or feeling physically exhausted, is one of the most common side effects of active cancer treatment, and about 30 percent of cancer survivors experience fatigue that continues long beyond treatment, even for years. Fatigue is treatable, though, and managing your fatigue is an essential part of your health care.

Cancer treatments most likely to cause long-term fatigue (one year or more) are chemotherapy, high-dose chemotherapy followed by a bone marrow transplant, and immunotherapy with interferon. Increasing activity and performing regular exercise (such as walking or riding a bike) are good ways to help manage and reduce symptoms of fatigue. You may also need to change dose of, stop or switch certain drugs or supplements. If your fatigue is severe, your doctor may recommend a psychostimulant drug such as armodafinil (Nuvigil), dextroamphetamine, methylphenidate or modafinil (Provigil).

Sleep disorders include difficulty falling asleep, staying asleep, poor sleep quality and daytime sleepiness. These problems can become chronic for some patients, even into survivorship, and can be caused directly by treatments or other side effects, such as pain, depression or fatigue.

Oftentimes, to treat sleep disorders, the underlying cause needs to be addressed and treated. Talk to your doctor about whether sleep medications commonly used to treat insomnia are appropriate for you. Non-medication treatments such as relaxation therapy, cognitive therapy and better sleep hygiene practices such as removing television from the bedroom, may also be effective.

### Lymphedema

Lymphedema occurs when lymph, the clear fluid that carries cells to fight infection, cannot flow normally through lymph vessels because of damage to lymph nodes or vessels or because lymph nodes have been removed. This causes an excess of fluid in body tissues that results in abnormal swelling, typically of an arm or leg (see Figure 1). Swelling ranges from mild to extreme, which may interfere with motion or function of the affected area. Lymphedema is most likely to occur after surgery that removes lymph nodes from the underarm, groin, pelvis or neck; the more lymph nodes removed, the greater the risk for lymphedema. Unfortunately, lymphedema is a lifetime risk for many survivors.

Preventing infection is an important part of managing lymphedema because an infection causes an increase in the production of lymph, which may lead to a buildup in affected areas. It’s also important to keep bodily fluids flowing properly to minimize swelling and control discomfort. Try to change position often while seated, keep your legs uncrossed and avoid restrictive clothing. Compression garments are often used to treat lymphedema, as they apply controlled amounts of pressure to specific areas of the affected limb, helping to regulate the flow of lymph and avoid buildup. Your doctor may also suggest that you see a lymphedema specialist.

Early treatment of lymphedema is important to help control swelling and discomfort, so be sure to call your doctor if signs of lymphedema persist for one to two weeks, including swelling in the breast, chest, shoulder, arm, hand, leg or foot; a heavy feeling, new ache or discomfort in an extremity; or less movement or flexibility in joints surrounding the affected area.
Contact your doctor or nurse immediately if the affected limb or body area feels hot, looks red or swells suddenly, or if you have a fever (oral temperature of 100.5 degrees F or higher) unrelated to a cold or flu.

NEUROPATHY
Peripheral neuropathy is a disorder of the peripheral nerves, which are the nerves outside the brain and spinal cord. It’s often the result of damage to sensory nerves caused by chemotherapy, targeted therapy, radiation or surgery.

Peripheral nerves control the sensations and movements of the arms and legs. Symptoms of peripheral neuropathy usually affect the extremities (hands and feet) first and include numbness and tingling, a decreased sensation of hot and cold, unpleasant sensations when touched, muscle weakness and cramping and balance problems. Pain may also occur and usually has a burning or electric shock-like feeling. These symptoms may make it difficult to carry out normal activities, such as buttoning clothes, picking up small items or writing. Muscle weakness and balance problems may cause an unsteady gait or difficulty with walking.

Peripheral neuropathy caused by chemotherapy or targeted therapy drugs can be either acute (short-term) or chronic (long-term). Chronic peripheral neuropathy may arise weeks or months after treatment has ended and is sometimes irreversible.

Peripheral neuropathy may be managed with exercises to ease discomfort and strengthen muscles, and with treatments and medications to relieve pain. Stretching exercises and isometric exercises (exercises involving flexing specific muscles for a period of time) can help decrease pain related to neuropathy and help you maintain your balance. Your doctor or nurse may suggest you see a physical or occupational therapist as part of a cancer rehabilitation program to help with strengthening exercises and finding ways to carry out everyday tasks with less discomfort.

Other strategies that have helped to relieve pain in some people are massage, acupuncture and transcutaneous electrical nerve stimulation (TENS). Some medications that have been used to relieve pain include corticosteroids, topical medications to numb the painful area and opioids for severe pain. Antidepressant drugs have also been found to help.

Some simple strategies include avoiding snug shoes or socks and extreme (hot and cold) temperatures, as well as taking part in regular exercise, such as walking. You should also take some safety precautions, as the decreased sensation in your hands and feet may increase the risk for injury. Keep your house well-lighted, remove area rugs and watch the floor in front of you as you walk. If you drive, make sure you can feel the pedals with your feet.

Call your doctor’s office when you first experience symptoms of peripheral neuropathy because early treatment offers the best chance of managing the neuropathy.

OSTEOPOROSIS
Osteoporosis occurs when bone cells that help rebuild bone (osteoblasts) don’t get replaced at the same rate as those that naturally break down bone (osteoclasts), resulting in weakened, fragile bones (see Figure 2). Loss of bone mass is common as you age, but it can also be caused by cancer and some cancer treatments.

If you are at an increased risk of osteoporosis, your doctor may order a bone density scan. If the test shows early signs of bone loss, he or she may prescribe a bone-modifying agent called a bisphosphonate. These work by slowing the rate of bone loss, helping to decrease new bone damage and promote bone healing. The use of bone-modifying agents has helped to reduce pain and bone complications, but they are linked with a rare but serious side effect called osteonecrosis of the jaw. Experts recommend that you visit your dentist to ensure your teeth and gums are healthy before you start treatment with a bone-modifying agent.

In addition to these agents, your doctor may also suggest physical therapy, which can enhance your quality of life by helping to manage pain, decrease the chance of bone fractures and increase mobility and safety. You can also help to keep your bones healthy by getting enough calcium and vitamin D and maintaining a healthy body weight.

ADDITIONAL RESOURCES
- Alliance for Fertility Preservation: http://fertilitypreservationalliance.org
- American Cancer Society: www.cancer.org
- American Society of Clinical Oncology (patient website): www.cancer.net
- Bone and Cancer Foundation: www.boneandcancerfoundation.org
- LIVESTRONG Foundation: www.livestrong.org
- National Cancer Institute: www.cancer.gov
- National Lymphedema Network: www.lymphnet.org
- National Osteoporosis Foundation: www.nof.org
- RESOLVE: The National Infertility Association: www.resolve.org
Managing the emotional effects of survivorship

After treatment, many survivors find themselves wondering, “What next?” The answer to that question will differ for every individual; some may work toward returning to life as it was before cancer and others will need to adjust to significant changes caused by the disease or its treatments. It’s important to remember that recovering from cancer isn’t just about physical changes; mental and emotional healing is also a factor.

Predicting exactly how survivorship will affect your emotions is impossible, as the mental and emotional impact is different for everyone. What’s often similar among survivors, however, is the distress and confusion that occur when negative feelings of stress, depression, anxiety, guilt or fear arise, rather than feelings of happiness and relief.

Mental health is an important part of the transition into survivorship. Studies show that approximately 10 percent of survivors experience some form of poor mental health. Many individuals are too quick to accept feelings of being a little “off” as a new normal. Recognizing the emotional challenges you may face and knowing when to ask for help are important to your emotional healing.

STRESS
Stress is the mental and emotional tension that results from an adverse or demanding circumstance such as cancer. And the reaction can have a physical effect as well. Your body reacts to a stressful situation by producing an excess amount of hormones, including adrenaline and cortisol. This stress response, also known as “fight or flight,” is your body’s chemical answer to a threat. Your heart rate and breathing quicken and your muscles tighten to prepare your body to either fight the threat or flee to safety.

This surge in cortisol levels, which normally fluctuates throughout the day, increases sugars in the bloodstream and affects the immune, digestive and reproductive systems. When cortisol levels remain high for prolonged periods (as with chronic stress), it can negatively affect your health by weakening your immune system, raising your blood pressure and cholesterol levels, increasing your risk for heart disease, and more. This can lead to distress, causing chest pain, headaches, upset stomach and trouble sleeping. Stress has a very real impact on your mental and physical well-being, so it’s important to manage stress before it becomes serious.

It’s common for survivors to feel stress as they transition from patient to survivor. After all, for the past several weeks, months or even years, you’ve focused most of your time and effort on fighting disease and getting better. But now that you’ve moved beyond treatment, you have to transition back to the duties and tasks of everyday life, all of which have probably been taking a backseat to your health. In addition to readjusting to the day-to-day...
to-day responsibilities, you may also be facing the stresses of:
- Finding or keeping a job
- Managing your finances and health insurance
- Dealing with your long-term side effects
- Rekindling and maintaining your relationships

An important key to managing stress is understanding that you don't need to do everything all at once. Make a to-do list and then prioritize. Be realistic about what you can accomplish in a given period of time, and be patient with yourself as you establish a new daily routine. Learning to say “no” and taking time to simply relax can also keep your stress level down. If over time you find you’re unable to adjust to your new routine and your stress levels remain high, it's important for your overall health to seek the appropriate help from a counselor or therapist.

DEPRESSION
Depression is a disorder consisting primarily of a depressed mood and a loss of interest or pleasure in normal activities. More complex than feeling sad or hopeless, a diagnosis of depression requires that you've felt at least five of the following symptoms every day for at least two weeks:
- Persistent sad, anxious or numb feeling
- Loss of interest or pleasure in hobbies and activities you once enjoyed
- Feelings of hopelessness
- Feelings of guilt, worthlessness or helplessness
- Fatigue and loss of energy
- Difficulty concentrating, remembering or making decisions
- Sleep problems
- Changes in appetite and/or weight
- Thoughts of death or suicide or suicide attempts
- Restlessness and irritability

For many cancer survivors, depression is a psychological reaction to the cancer experience as a whole. However, if left untreated, lingering side effects can cause depression. Certain ongoing treatments or maintenance therapies, such as chemotherapy or hormone therapy drugs, can also cause or contribute to depression. Many cancer survivors who have depression do not talk to their doctors about it because they think depression is “expected.” But depression can and should be treated.

Milder forms of depression may be alleviated by counseling alone (without medications), while moderate or severe depression is typically managed with a combination of psychological treatment and medications (antidepressants). Psychological treatment may include individual psychotherapy, which explores emotional issues that contribute to depression, and/or cognitive-behavioral therapy, which helps change negative thought patterns and behaviors. Cancer support groups can also be helpful, as are a range of complementary therapies, such as meditation, art therapy, massage therapy, music therapy, writing therapy, exercise and stress-relieving strategies (such as deep-breathing exercises and guided imagery). In addition, support from family and friends can help you better cope with daily life and perhaps reduce your risk for depression.

When antidepressants are necessary, many types are available. The antidepressants most often used for people with cancer belong to a class known as selective serotonin reuptake inhibitors (SSRIs). Tricyclic antidepressants may be used as well, although they generally have more side effects than the SSRIs. Another class of drugs, known as psychostimulants, has also shown some promise in the treatment of depression when given alone or in combination with a different type of antidepressant drug.

An increasing number of people have turned to other forms of therapy when seeking comfort both during and after treatment. For some people, writing therapy is preferred over visiting a therapist because it’s private and available whenever it’s needed.

Writing after your cancer treatment can help you understand your experience, work through those feelings and reflect on what your disease has meant to you, your family and your friends. Common types of therapeutic writing include:
- Free writing, also called journaling, is simply writing what’s on your mind without censoring yourself. Free writing is helpful because it takes your endless string of thoughts and creates logical sentences. By writing your thoughts down, you can acknowledge and accept your feelings about your past, present or future on your own.
- Poetry can be healing, but it can also be intimidating to many people. You can practice writing poetry by recalling specific moments from past experiences and describing them. Write about what you saw, smelled, felt, heard and tasted, along with the emotions associated with these sensations.
- Letter writing is beneficial even if the intended recipient never reads it. It can be helpful to write down your feelings in a way that’s intended to tell someone the truth without a face-to-face encounter. Although your letters might be read only by you, creating that dialogue is an important part of the healing process.

Writing therapy can also have physical benefits. By continuing to write about your present experiences, you may track changes in your body more easily. Tracking your symptoms, physical activity, diet and other aspects of your daily routine can be both useful and comforting. If you become aware of negative changes like extreme fatigue or loss of appetite, it could be a sign that you need to visit your doctor to check for signs of recurrence or possible late side effects from treatment.
ANXIETY
Anxiety is a feeling of worry and unease and is often characterized by the following symptoms:

- Difficulty focusing thoughts
- Unexplained trembling or shaking
- Muscle tension
- Restlessness
- Irritability or a quick temper
- Dry mouth

Anxiety about your future can strike as soon as your cancer treatments end and can continue for as long as the anxiety is left untreated. If your symptoms are severe, they can start to interfere with your day-to-day life and even becoming debilitating. Therefore, it’s important to seek help if you believe you may be suffering from anxiety.

Moderate to severe anxiety is often treated with medication, therapy or a combination of both. The medications most commonly used to treat anxiety are antidepressants, anti-anxiety drugs and beta-blockers to control some of the physical symptoms. Many people who suffer from anxiety also benefit from joining a self-help or support group, where they can express their feelings and share their experiences with others. Stress management techniques, such as meditation, physical activity and deep breathing exercises, can help lessen anxiety as well.

GUILT
It’s not unusual for cancer survivors to feel some level of guilt. Some feel like they’re to blame for their disease and everything that happened. Others worry that they placed too much of a burden on their loved ones, and some even wonder why they survived while others with a similar condition weren’t as lucky.

If you’re feeling guilty, it can be helpful to talk through your feelings with a counselor or therapist. He or she can help you identify the cause of your guilt and teach you how to work through it. Alternatively, you might find that you can lessen your guilt by somehow giving back to the cancer community. Helping others can provide a sense of purpose and well-being that can override any blame you may be placing on yourself.

FEAR
Many survivors live with the fear that their cancer will come back. Making long-term plans becomes difficult, and every ache and pain triggers a concern that the cancer has returned. Developing a comprehensive follow-up care plan can help calm these fears.

Going to your follow-up visits may involve screening exams and diagnostic tests in order to monitor for potential cancer recurrence, which can trigger a spike in fear. It’s normal to feel anxious and even overwhelmed just before your next mammogram or CT scan. It may be beneficial to take someone with you to your follow-up appointments for support. And if you find yourself distracted leading up to your visit, it can be helpful to avoid making big decisions or trying to complete important tasks immediately before the appointment.

As more time passes you will begin to trust your body again, and the fear and anxiety will lessen; however, they may never completely disappear. Do your best to stay focused on the present and to remind yourself that you are a survivor and that history does not always repeat itself. Doing what you can to live as healthfully as possible, such as eating right, exercising and staying busy with activities you enjoy, can also help. And by being honest about how you feel, you can help yourself to move forward; only after you acknowledge your fears can you begin to face them.

LIVESTRONG at the YMCA
In 2007, LIVESTRONG and the YMCA of the USA joined forces to create a 12-week exercise program designed for cancer survivors. This program, offered at select YMCAs at little to no cost for participants, helps individuals improve physical fitness and strength, lessen the impact of treatment side effects, improve quality of life and establish supportive relationships. To date, the program has served over 30,000 survivors in more than 400 locations nationwide.

You don’t have to tough it out on your own. There’s a program there to help you regain your confidence, your coordination, your muscles and your zest for life.

— Sam, program participant

To learn more, contact livestrongattheymca@ymca.net

ADDITIONAL READING

Man Cancer Sex and Woman Cancer Sex, by Anne Katz, address sexuality after a cancer diagnosis—Available from the Oncology Nursing Society online bookstore at www.ons.org/store/books.

THE REBUILDING PROCESS
All of these emotions—stress, depression, anxiety, guilt and fear—are valid, understandable and possibly even expected in cancer survivors. However, they can become serious if they’re ignored. Therefore, an important part of survivorship involves acknowledging your emotions—both the good and the bad. From there, you can learn to accept them and seek treatment as necessary.

If your emotions are affecting your daily life, it’s important to seek counseling or therapy. Your doctor or another member of your cancer care team can refer you to a mental health specialist who has experience working with cancer survivors. Your cancer center may even have a qualified employee on staff. Additional resources you can turn to for referrals include the Association of Oncology Social Work (www.aosw.org) and the American Psychosocial Oncology Society (www.apos-society.org).

ADDITIONAL RESOURCES

- American Cancer Society: www.cancer.org
- American Psychosocial Oncology Society: www.apos-society.org
- American Society of Clinical Oncology (patient website): www.cancer.net
- Livestrong at the YMCA: www.cancer.gov
- LIVESTRONG: www.livestrong.org
- LIVESTRONG Cancer Navigation Services: 855-220-7777
- National Cancer Institute: www.cancer.gov

Surveillance and monitoring for cancer survivors

As a survivor, your cancer diagnosis and primary treatment are now behind you. It is still important, however, to be vigilant in your care. Some cancers may come back, and you may also be at risk for a second cancer. It’s important to adhere to your follow-up care plan and stay on top of your health.

RECURRENT CANCER
When cancer that’s the same type as the original cancer comes back, it’s called recurrent cancer. For example, you may have beat lung cancer, but if in a few years you again develop lung cancer, it’s called recurrent lung cancer. Recurrence can happen weeks, months or even years after treatment stops, and the cancer may come back in the same area of the body as the primary cancer (local recurrence), in an area of the body near the location of the primary cancer (regional recurrence), or in a completely different area of the body (distant recurrence).

Although the reasons are often unknown, cancer sometimes comes back because tiny amounts of cancer cells occasionally survive treatment and remain in the body undetected. These lingering cells may start to grow and multiply until, eventually, tests can again detect them.

While doctors cannot know for sure which patients will experience cancer recurrence, they’ll often make predictions based on the recurrence patterns of certain cancer types. Be sure to ask your doctor for more information about your recurrence risk profile.

SECOND CANCER
Cancer that’s different than your original diagnosis can sometimes develop even after you’ve finished battling the first cancer. For example, you may have beat ovarian cancer, but a few years later you develop breast cancer. Several factors have been linked to the development of a second cancer, including:

- **Cancer treatments:** Research has shown an increased risk for radiation-related second cancers in patients who received radiation as part of their treatment for a primary cancer.

- **Cancer types:** While it’s not yet clear if second cancers may be caused by the original cancer or its treatment (or a combination of the two), some of the primary cancer types linked to the development of a second cancer include:
  - **Solid tumor cancers such as lung, stomach, bladder, breast, thyroid and bone.**
  - **Bladder, breast, thyroid and bone.**
  - **Breast cancer.** Several factors have been linked to an increased risk for second cancers, including:
  - **Radiation treatments:** Tissues closest to the radiation site are most at risk for developing a malignancy. Additionally, some chemotherapy drugs are tied to an increased risk for second cancers, including chemotherapy-related leukemia and some solid tumor cancers such as lung, stomach, bladder, breast, thyroid and bone.

The fight against cancer may not end with the initial treatment. Even survivors who’ve beat their cancer may need to take medications that can prevent the disease from recurring; this is called maintenance therapy. You may also be prescribed medication to prevent or manage possible late effects from cancer treatment.

The word “adherence” means that a patient is taking the right dose of the right drug at the right time. From chemotherapy and hormone therapy to vaccines and other drugs, your ability to take your medication exactly as prescribed by your physician can greatly affect your long-term health as a survivor. When patients don’t follow their scheduled regimen exactly as prescribed, it’s called non-adherence.

**COMMON CAUSES OF NON-ADHERENCE**
One-third of cancer patients admit they don’t always follow the exact prescribed regimen, and more than half admit they occasionally forget to take a dose. Known reasons of non-adherence include skipping doses to try to avoid side effects, splitting doses to save money, not filling (or refilling) prescriptions because of high copays or lack of insurance, complex treatment regimens, or a belief that the treatment is unnecessary, especially in patients who don’t have symptoms. Taking too much medication is also a form of non-adherence and can be extremely dangerous.

While most patients often start their medication regimen with the best of intentions, rates of adherence tend to taper off over time. For example, medication adherence for women taking tamoxifen for breast cancer is generally high during the first year, but then gradually decreases over the five years of recommended therapy—even though it’s proven to reduce the rate of recurrence and extend lives when taken as prescribed.

Many physicians believe that treatment fatigue, which is the feeling of wanting to escape the confines of cancer treatment, may contribute to reduced medication adherence in individuals with long-term treatment plans. Treatment fatigue may also derive from a cancer patient’s unwillingness to accept cancer as a part of his or her life.

Whether you are taking medication as maintenance therapy or to help manage late effects of cancer treatments, survivors who fully understand and actively participate in their follow-up care are more likely to transition to a healthier survivorship while avoiding potentially severe and unnecessary complications that come with medical non-adherence.

If cost is a factor in medication non-adherence, there are financial resources available that can help (see Financial Assistance on page 24).
types associated with an increased risk of second cancers include Hodgkin lymphoma; cancers commonly associated with tobacco use such as lung, kidney, esophagus and urinary bladder; breast cancer; cervical cancer; colon cancer and childhood cancers.

- **Inherited and/or acquired gene mutations:** When certain genes mutate due to inherited syndromes (passed down from generation to generation) or acquired circumstances (changes that arise throughout a person's lifetime), the risk for various cancer types increases. For example, inherited mutations in the KIT gene can cause hereditary gastrointestinal stromal tumors (GISTs).

- **Personal characteristics:** Age (both current and at the time of primary treatment), gender, race, ethnicity and health status are among the personal characteristics that can play a role in your risk for developing a second cancer.

- **Lifestyle choices:** Various unhealthy choices, including poor diet, physical inactivity, smoking and excessive alcohol use, might increase the chance of a second cancer. For example, colon cancer survivors may be at an increased risk for developing other digestive tract cancers that share similar risk factors such as obesity and diet.

The risk for developing a second cancer is small – it happens in only 1 to 3 percent of cancer survivors – but it’s still important to talk to your doctor about what to look for and what to do to help minimize your risk.

**MONITORING YOUR HEALTH**

Following treatment for your primary cancer, your doctor will design a follow-up care plan to monitor your health and check for a potential recurrence or second cancer. Your plan might include physical examinations, blood tests, imaging tests and/or scheduled cancer screenings.

There are multiple organizations that implement screening guidelines for major cancers. The National Comprehensive Cancer Network (NCCN), a non-profit alliance of leading cancer centers, recommends cancer screening guidelines that are nationally recognized as the standard for clinical policy in cancer care. The US Preventative Services Task Force (USPSTF), a national panel of experts in prevention and medicine, as well as the American Cancer Society (ACS), a national health organization, also have recommended guidelines for cancer screening tests. Multiple factors influence these recommendations, including the amount of research conducted, the quality of the screening, the risk level of the individual, and the person's health history.

Not all of the guidelines recommended by these groups are the same, and not every guideline is appropriate for cancer survivors, so you should talk to your doctor about the schedule that’s right for you. If signs of cancer are detected, your doctor will run various diagnostic tests to learn as much as possible about the disease. He or she will then talk to you about your treatment options.

**FIRST AND SECOND CANCERS AMONG ADULT SURVIVORS**

<table>
<thead>
<tr>
<th>Primary cancer</th>
<th>Commonly associated second cancers*</th>
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<tbody>
<tr>
<td>Breast</td>
<td>Female breast (contralateral breast) / Lung / Colon / Ovarian</td>
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<tr>
<td>Colon</td>
<td>Prostate / Colorectal / Lung / Female breast / Bladder</td>
</tr>
<tr>
<td>Bladder</td>
<td>Prostate / Lung / Bladder / Colon</td>
</tr>
<tr>
<td>Hodgkin Lymphoma</td>
<td>Lung / Female breast / Non-Hodgkin lymphoma / Acute non-lymphocytic leukemia (ANLL)</td>
</tr>
<tr>
<td>Testicular</td>
<td>Prostate / Lung / Bladder</td>
</tr>
</tbody>
</table>

*According to the American Society of Clinical Oncology: Standardized Incidence Ratio (SIR) and Excess Absolute Risk (EAR) for Selected Second Cancers among Adult Survivors

**SECOND CANCER RISKS**

*The numbers presented in these graphs are the “observed-to-expected” (O/E) ratios for certain second cancers among men and women. This means the number of expected second cancers was compared to the number of actual second cancers diagnosed among cancer survivors. An O/E that is higher than 1 indicates a higher than expected number of diagnosed second cancers among the studied survivors.

**BY THE NUMBERS**

Source: American Cancer Society, Surveillance and Health Services Research, 2014

PatientResource.com
LIFESTYLE CHANGES

Once you’re finished with primary treatment, living a healthy lifestyle is still very important. And while you can’t necessarily prevent a cancer recurrence with good nutrition, more and more research is showing a number of health benefits from eating right and exercising.

NUTRITION’S ROLE IN PREVENTING RECURRENCE

The American Cancer Society recommends that cancer survivors follow the same nutrition guidelines that are recommended to help prevent cancer. A recent study of breast cancer patients has shown that the rate of recurrence was higher in women at an unhealthy weight who didn’t eat an adequate amount of fruits and vegetables. For men, saturated fat has been linked to a higher rate of prostate cancer coming back.

Poor nutrition also may lead to obesity, which has been linked to many cancers and diseases, such as heart disease and diabetes.

GOOD NUTRITION & PHYSICAL ACTIVITY WORK TOGETHER FOR A HEALTHIER YOU

As you move forward into survivorship, staying physically active becomes increasingly important to maintaining your health. Exercise and physical activity help prevent and treat obesity, which can lead to diabetes, heart disease and osteoporosis. Exercise can also help prevent muscle wasting as a result of inactivity, and may help reduce the lasting or late effects of cancer treatment. A number of studies have also shown that people with certain cancers who also maintain regular physical activity have a reduced risk of cancer recurrence.

The American Cancer Society (ACS) recommends that cancer survivors take part in regular physical activity and resume normal daily activities as soon as possible after diagnosis and treatment, and well into survivorship. ACS recommends at least 150 minutes of exercise per week as well as strength training exercises at least two days each week. You should stay as physically active as possible and increase your activity level over time.

Many people can start and maintain their own exercise regimen safely, but you may have better results with the help of an exercise specialist or physical therapist. Either way, be sure to talk to your doctor before starting any exercise program. Ask about exercises you can safely do and any limitations you may have.

REHABILITATION AND SIDE EFFECT MANAGEMENT

Rebuilding strength and flexibility are important for your recovery and to help prevent further injury. Physical activity can also help decrease the side effects of cancer treatment, including fatigue, one of the most common treatment-related side effects.

Other side effects, such as lymphedema, may also be managed with the help of exercise. Certain activities can help regulate the flow of lymph by helping lymph vessels move fluid away from the affected area, reducing the swelling.

EXERCISE AND IMPROVEMENT ON MOOD AND ENERGY

In addition to improving your physical health, exercise has also been shown to reduce anxiety, depression and fatigue. Physical activity is also a great way to reduce stress, which is important to your overall health, and is a natural way to boost your mood, offering drug-free relief for many of the emotional side effects of cancer and its treatments.

HEART DISEASE

Heart disease broadly refers to coronary heart disease, heart attack, congestive heart failure and congenital heart disease. A diet that’s high in fat, salt and cholesterol can contribute to the development of heart disease, as can obesity.

While heart disease isn’t a risk factor for cancer, various cancer treatments, including chemotherapy, radiation therapy and hormone therapy, can cause or worsen heart disease; patients who have heart or vascular conditions before their cancer treatment are especially vulnerable. One study showed that women who had radiation to treat breast cancer increased their risk of heart disease by 3 percent on average.

To combat the increased risk, it’s important for cancer survivors to follow nutrition guidelines, including limiting the consumption of red and processed meat. Protein can come from many healthy sources, so try to go meat-
less several days a week, incorporating other protein sources for your meals, such as a black bean burrito or a hearty lentil soup.

**DIABETES**

Diabetes is a condition in which blood glucose (sugar) levels are too high. There are two types of diabetes: Type 1 and Type 2. In Type 1 diabetes, the immune system destroys the body’s ability to produce insulin, which results in an inability to convert glucose into energy. Type 1 diabetes cannot be prevented, typically arises during childhood and accounts for 5 to 10 percent of all cases of diabetes. Type 2 diabetes is characterized by the body either having too little insulin or being unable to use insulin effectively. Among the causes of Type 2 diabetes are obesity, high blood pressure and a high-fat and carbohydrate diet. This type of diabetes occurs most often in adults and accounts for 90 to 95 percent of all cases.

People with diabetes – Type 2 specifically – are at a significantly higher risk for many types of cancer, including liver, pancreas, uterine and others. A recent study also linked diabetes to a higher risk of recurrence of colon cancer. If diabetes is left untreated and blood sugar levels remain high for an extended period of time, significant damage to the heart, eyes, kidneys and nerves can occur. To prevent this, limit the amount of sugar you consume, participate in regular physical activity and take prescribed insulin and blood sugar medications as recommended by your doctor.

**EMBRACING HEALTHY EATING**

Making healthy food choices after treatment can help you regain your strength, help your body heal itself and help you feel better overall. To help you maintain a healthy diet, try preparing meals that you enjoy, are simple to make and can be frozen to eat later. Make the process easier by keeping your kitchen stocked with fruits, vegetables and healthy grains. How you cook your food is also important: You can reduce the amount of fat by broiling, grilling, roasting or steaming your meals. Reduce your consumption of fat, salt and sugar, and avoid smoked and pickled foods. When it comes to alcohol, always drink in moderation.

**IMPORTANCE OF VARIETY AND PORTION SIZES**

No single food has all of the vitamins and nutrients necessary to maintain a healthy diet. Eat a variety of foods from all the food groups, including raw and cooked fruits and vegetables; whole wheat, grains and oats; and beans, lentils and peas so that you can get all of the nutrients your body needs from your food.

Try to eat five to nine servings of fruits and vegetables daily. Pick out a new fruit, vegetable or whole-grain product every time you go grocery shopping to add variety to your diet; you may find something new you really like. Also, choose low-fat milk products like 1-percent or skim milk and lower-fat cheeses, such as mozzarella.

If you’re trying to control your weight, it’s important to watch your portion sizes. A good serving of meat, fish or poultry is about 3 to 4 ounces, which is approximately the size of a deck of cards. Include protein at each meal, and a smaller serving with snacks. Substituting more fruits and vegetables, which are low in calories and high in fiber, for higher-calorie side dishes and snacks may help with weight control as well.

**AVOIDING FAD DIETS**

There seems to be an endless variety of specialized diet plans marketed to consumers, each touting extraordinary results. The grapefruit diet, the raw food diet, the Mediterranean diet, Atkins, intermittent fasting—these are just a few of many options with devoted followers supporting their benefits. While many of these include some legitimate approaches with a few proven benefits, beware of any plan that promises a quick fix, or one that ignores basic nutrition. These diets are usually not sustainable over the long term. The best option involves a shift in your overall approach to nutrition. By adopting healthier habits regarding food, you can establish a more sustainable and nutritious lifestyle.

**BE CAUTIOUS OF HERBS AND SUPPLEMENTS**

Most of the time, the vitamins and minerals your body needs to be healthy are better obtained through eating the right foods rather than taking a supplement. However, many people are tempted to start taking various over-the-counter herbs and supplements based on advertisements that boast about their benefits. It is important to know that many of these substances are not regulated by the FDA, so talk to your doctor before you start any new regimen.

**BENEFITS OF TALKING WITH A DIETITIAN**

As you transition into survivorship, you may have questions about how to begin or maintain a healthy diet. You should talk to your dietitian about any food or diet restrictions you may have, and then determine what your nutrition goals should be. A dietitian can help you reach those goals, which may include weight loss, weight gain, or just learning how to maintain a healthy diet and lifestyle after treatment. Your dietitian can help you create a nutritious, balanced eating plan, tailored specifically to you. A member of your health care team should be able to refer you to a dietitian in your area.

**IF LIVING A HEALTHIER LIFESTYLE SEEMS IMPOSSIBLE**

No one expects you to be able to immediately begin doing all of the things that are listed here. Often, those who are most successful at adopting and sustaining a healthier lifestyle do so by making small changes over time. For example, if you plan to cut back on soda, reducing the amount of soda you drink daily by one bottle or can is a great way to start. As with any major change in your life, adjusting can take time. Allow yourself to make progress one step at a time and enjoy reaching each small goal along the way.

**THE CONSEQUENCES OF CONSUMPTION**

Alcohol consumption has been linked to many health problems, and the risk of developing those problems increases with the amount of alcohol you consume. Long-term, heavy drinking can even lead to an increased risk of developing certain cancers, and may increase your risk of cancer recurrence or a second cancer. The American Cancer Society recommends no more than two alcoholic beverages per day for men and no more than one per day for women. Certain groups of people, however, should not consume any alcohol, including those taking medicines that interact with alcohol and those people with certain medical conditions, such as liver disease. Although different drinks contain different percentages of alcohol, a standard drink is generally 12 ounces of beer, 5 ounces of wine or 1.5 ounces of an 80-proof liquor.

There are many ways alcohol is believed to increase cancer risk, however, the effects of alcohol on cancer recurrence aren’t well known. So talk to your doctor about alcohol consumption after treatment, and discuss how alcohol may affect any medications you may be taking and your risks of developing late side effects that may be caused or worsened by alcohol.
Now that your primary cancer treatment has ended, you may find that your sexual health and function are not the same as they once were. Research has shown that most cancer survivors experience some type of sexual dysfunction at some point in their journey, yet many do not talk about it with their doctors. Sexual health is important to your recovery and overall well-being, and several options are available to help you resolve or manage sexual health problems.

COMMON PROBLEMS AND THEIR TREATMENTS

Many survivors face post-treatment sexual difficulties such as a decreased libido (sex drive), the inability to achieve or maintain arousal or pain during intercourse. Emotional side effects, such as depression or an altered body image can also impact sexual health in a negative way.

Men

The most common 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 physical, psychological and medication elements:

- **Physical:** Your doctor will likely look for any physical factors that may be contributing to your ED, such as high blood pressure or diabetes. Sometimes controlling those issues will, in turn, correct ED.
- **Psychological:** Is your relationship with your partner tense or strained? Are you in a new relationship? Dealing with your feelings can help successfully treat ED. If appropriate, your doctor may refer you to a therapist.
- **Medications:** If ED persists, your doctor might prescribe one of several drugs, such as sildenafil (Revatio, Viagra), vardenafil (Levitra, Staxyn) or tadalafil (Adcirca, Cialis). However, drugs for erectile dysfunction may not be appropriate for every man, so talk to your doctor about the risks and benefits. Secondary treatment options such as a vacuum device or penile injection therapy may be appropriate for some men.

Women

The sexual problems that most commonly affect female cancer survivors include vaginal dryness and discomfort and pain during intercourse. Correcting these problems can help boost libido, arousal and ability to reach orgasm, and several remedies are available:

- **Moisturizers:** Nonhormonal, over-the-counter vaginal moisturizers – commonly gels administered as a vaginal suppository or through a tampon-shaped applicator – can help relieve vaginal dryness when used multiple times per week.
- **Lubricants:** Water-based vaginal lubricants, which are applied inside the labia, can help reduce pain during intercourse.
- **Dilators:** Vaginal dilators gradually stretch the walls of the vagina, which can help decrease vaginal discomfort.
- **Pelvic floor exercises:** a gynecologist who specializes in pelvic floor strengthening can be helpful for women dealing with vaginal pain, urination during intercourse, and other sexual dysfunction symptoms.

**Men and Women**

Somebody image issues trigger sexual dysfunction. Things such as a mastectomy, your hair not yet growing back, or having an ostomy may cause concerns regarding your appearance. There are more solutions than you may think to help you cope with any body image problems that may be a factor in sexual dysfunction. A psychotherapist who specializes in cancer survivors can help you overcome some of the psychological aspects contributing to these issues.

**TALKING TO YOUR DOCTOR**

Many people are too embarrassed to speak up about sexual health issues; however, sexual health contributes to quality of life, so do your best to overcome the awkwardness and talk to your doctor or nurse navigator about any sexual difficulties you’re experiencing. When you do, be as specific as possible to better enable your doctor to help you work toward a solution. If your doctor is unable to provide the necessary care, he or she may refer you to a specialist or recommend that you join a support group. The road to sexual health is different for everyone, but it always starts with a conversation.

**TALKING TO YOUR PARTNER**

Open communication is the key to maintaining a healthy intimate relationship. Sit down with your partner and openly share your concerns, fears and other feelings; then allow your partner to do the same. You might want to talk about ways to be intimate other than with sexual intercourse. Depending on your situation, you might consider including a professional counselor or therapist. Many couples have benefited from this third-party expertise and have grown closer because of it. Lastly, do your best to set aside one-on-one time with your partner to rediscover and strengthen the element of intimacy in your relationship.

**LEARNING TO LOVE YOURSELF**

While all of this information and advice is undeniably important, perhaps the best thing you can do for your sexual well-being is learn to love yourself. After going through cancer treatment, many survivors report feeling disconnected from their bodies. If this is true for you, an important first step toward reclaiming your sexuality is becoming comfortable with your body. Embrace your new self, including all the scars, discolorations and other “battle wounds” that are a result of your cancer treatment. People around you, including your partner, will pick up on that self-acceptance and respond in kind. Love yourself first; everything else will follow.
Thankfully, my husband was amazing and kept me grounded, and the rest of my family tried their best to cheer me up. I was always going in for treatment or blood work, but thankfully I had support from countless family members offering to give me a ride, watch the kids or just to offer encouragement. For six months I went in for chemo injections (the ABVD cocktail) every two weeks that would take about eight hours to administer. I had stopped nursing my baby, but I was thankful that doctors didn’t install a port in my chest so that I could still hold and snuggle my boys throughout treatment. They helped me to focus.

I was lucky when it came to side effects. Other than losing my hair, the bone marrow test was the worst part of treatment. My white blood cell counts began falling during the second half of my treatment, so I had to administer daily shots of filgrastim (Neupogen) to boost my white blood cell count. The side effects of that were actually harder than the chemotherapy itself. For months I experienced the sensation of shock waves pulsing deep down in my bones. It was an unbearable ache that I’ll never forget.

So much of a woman’s identity is in her hair, and I felt ashamed when mine started to fall out. I remember bursting into tears while looking at wigs with my parents because of how fake they looked. Thankfully, I found a ministry that provided human hair wigs that are dyed and styled to match each patient’s original hair. For the first time I thought, “OK, this will work.” And it did.

Everything surrounding cancer treatment has significantly improved since I was diagnosed nearly two decades ago. There is a plethora of information at your fingertips and millions of cancer survivors ready and willing to share their stories and give you advice. Take advantage of their experiences and have faith that no matter what, you are in the middle of writing your own survivor story.
Cancer patients often rely on spirituality or religion to help them cope with their disease during treatment. The two terms are frequently used interchangeably; however, for many people they mean different things. Spirituality often refers to how individuals find and express meaning and purpose and how they connect to everything around them, whereas religion is typically defined as an organized set of beliefs or practices, often within a group. Studies have shown that strong religion and spirituality (regardless of your religious practices) are linked to an improved quality of life and being better able to cope with a cancer diagnosis, treatment and survivorship.

Survivors may begin to look at religion or spirituality differently, even throughout the transition into survivorship. It’s common among survivors and their families to wonder why cancer has become a part of life, what it means and how to move forward. You may want to redefine the meaning in your life and make sense of your cancer journey. Some survivors find greater strength, others question their beliefs, and many gain new focus. Developing a sense of meaning and peace of mind through spirituality may help you on your road to enjoying life, experiencing better overall health and living longer after cancer.

**FEELINGS OF DOUBT**
The sense of doubt that some cancer survivors may feel can lead to confusion and questions about the meaning of life and your purpose. This is common. Some people find strength in support from family, friends, the community or church. It may help to talk about your feelings with a loved one, close friend, counselor or support group. In addition to all the answers you may seek, religion and spirituality can offer a way for survivors to connect with their community and other survivors. For many, sharing their story and working to help others cope with a similar experience helps them find new understanding.

**SEEKING NEW MEANING AND PERSPECTIVE**
Many survivors gain a new focus after cancer. You may question your priorities in life, think more closely about what’s important to you, find deeper appreciation or enjoy a renewed sense of spirituality. Or, you may be working toward those things but need support. Sometimes to gain new perspective, it can help to read uplifting stories, pray, meditate, or speak to a spiritual counselor. No matter how your spirituality may have changed, it’s important to recognize all that you have been through and know that it’s normal to feel a sense of grief for what you may have lost from your life before cancer.

As a survivor, you will likely look at your priorities and realize many of them have changed. You may want to spend more time doing things you enjoy and spend more (or less) time with certain people in your life. It’s important to share this with your loved ones, as your changing priorities can cause some initial confusion to those around you. By discussing it, you may not only develop a clearer picture of the things you want in life but you may also help those around you understand, accept and support the decisions you have made.

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Learn more about laughter as therapy from the Association for Applied and Therapeutic Humor at [www.aath.org](http://www.aath.org)
You have gained a vast wealth of knowledge and experience as a cancer survivor, putting you in a unique position to truly make a difference in other people’s lives. By sharing what you’ve learned throughout your cancer journey, you can give back to the cancer community, help others and empower yourself.

**TYPES OF VOLUNTEERING**

You have many opportunities to give back, including several in each of the following categories:

- **Advocacy:** If you feel strongly about a specific cause, such as cancer research funding or health care access, you can join and/or develop a local or national effort to effect change. Advocacy is all about raising awareness and changing opinions.

- **Communication:** If you’re open to sharing your experiences and listening to others’ concerns, consider signing up to be a phone or email cancer hotline counselor or volunteering to lead an in-person or online cancer support group.

- **Education:** Cancer and its treatment are foreign concepts to many people, so teaching others about the disease and the health care world can be incredibly beneficial to those you are working with. You can teach sessions or lead discussions at a community center or even some medical facilities about several topics, including specific types of cancer, legal services, health insurance, caregiving, necessary equipment (e.g., wigs, lotions, etc.) and much more. Your knowledge will be greatly appreciated.

- **Fundraising:** Many national and local organizations often host fundraisers in an effort to raise money and awareness about cancer. You can sign up to organize an event, or volunteer at fundraising events, such as races, tournaments, auction events and dinners. If you enjoy this kind of work, consider planning a brand new event in your area; setting specific goals and reaching out to others can help you get started.

- **Hospitality:** Survivors with great customer service skills provide a comforting presence for patients going through treatment. You can volunteer your time at cancer resource centers by handling inventory, merchandising and customer care. Many support centers also need help preparing meals or planning activities for patients.

No matter how you choose to give back, doing so will not only help many others, it will put you in touch with new people, provide a sense of accomplishment and help you to heal more fully as you move forward with your life.

**HOW TO FIND VOLUNTEER OPPORTUNITIES**

There are volunteer opportunities for cancer survivors everywhere; you just have to know where to look. Start by asking your family members, friends and others in your community whether they know of an individual or organization that could benefit from your help. You can also browse your local newspapers and the community bulletin boards at your supermarket, library or church for volunteer listings. Other opportunities can be found by calling hospitals, cancer centers and cancer-related groups and organizations. Ask about their volunteer programs and find out how you can get involved. Many national cancer advocacy groups host local chapters; by reaching out you may be able to connect with other volunteers in your area.

**WHEN TO START VOLUNTEERING**

As a new cancer survivor, you may want to begin volunteer work right away. Just be sure to give yourself enough time to adjust to life after cancer before trying to help others. You want to be sure that you do not commit to too much, too soon, as you adjust to working, returning to routine family life and re incorporating other daily demands that may have taken a backseat while you were in treatment.

As part of your volunteer goals, consider what is reasonable for you to take on and how you can best work toward making a difference in the lives of others. You may find that you have several hours each week to donate to volunteer work, or one day a month. Create a schedule that works best for you and your family. Planning out your commitments ahead of time can help you prevent starting volunteer work only to find that you are unable to sustain your commitment.

**ADVOCACY WORK HAS WIDESPREAD EFFECT**

Caesar Blevins is an advanced prostate cancer survivor who participates actively with the local Prostate Cancer Networking Group. When he was first diagnosed, he was a very private person and knew little of the disease. “My work with the advocacy group empowered me to speak out,” he said. “I became more knowledgeable, mentally stronger and passion-driven. And I find that focusing on the people I’ve helped through advocacy also keeps me positive and helps me to remember: Don’t give up, because I’m still alive.”

The advocacy work he does has not only made an impact in his life; it’s helped countless others in the battle against cancer. His words of encouragement can be heard throughout the cancer community, as a boisterous and energetic Bingo host at the local American Cancer Society Hope Lodge to his kind posts to friends in treatment on the group’s Facebook page.

“This disease doesn’t affect just one man; it affects all those who love him. And if my being an advocate encourages even one man to go get checked — regardless of the results — I’ve done good work.”

Caesar has become one of the driving forces behind the group’s community and social media outreach, and he shares a similar message with all of the patients who turn to him: “Look for other survivors and find a support group — because we are StrongerTogether.”

The Prostate Networking Group can be found on Facebook and Twitter (@ProstateNetwork)

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PatientResource.com
State Health Insurance Assistance Programs ...................................... www.shiptaxcenter.org
Stupid Cancer .............................................................................. www.stupidcancer.org

HOSPICE & HOME CARE
American Hospice Foundation ..................................................... www.americanhospice.org
Caring Connections ..................................................................... www.caringinfo.org
Hospice Education Institute Inc. .................................................... www.hospiceworld.org
Hospice Foundation of America .................................................... www.hospicefoundation.org
International Association for Hospice and Palliative Care .............. www.hospicecare.org
Kansas City Hospice & Palliative Care ........................................ www.kansascityhospice.org
National Association for Home Care & Hospice ......................... www.nahc.org
National Hospice and Palliative Care Organization ....................... www.nhpco.org
The Oley Foundation ..................................................................... www.oley.org
Visiting Nurse Associations of America ........................................ www.vnna.org

MENTAL HEALTH SERVICES
American Psychosocial Oncology Society Helpline ......................... 866-276-7443
Association of Oncology Social Work ........................................... www.aosw.org

NUTRITION
American Cancer Society ................................................................ www.cancer.org
CancerCare .................................................................................. www.cancercare.org
Food for Life Cancer Project ...................................................... www.fgrün.org/health/cancer-resources
LIVESTRONG Foundation ......................................................... www.livestrong.org
OncoLink ..................................................................................... www.oncolink.org
PearlPoint Cancer Support ......................................................... www.pearlpoint.org

PAIN MANAGEMENT
American Chronic Pain Association .............................................. www.theacpa.org
Cancer Pain Research Consortium .............................................. http://cancerpainresearchconsortium.org
LIVESTRONG Foundation ........................................................... www.livestrong.org
The Resource Center of the Alliance of State Pain Initiatives ......... www.trc.wisc.edu
U.S. Pain Foundation .................................................................... http://uspainfoundation.org

PATIENT ADVOCACY
Academy of Oncology Nurse Navigators ......................................... www.aonnonline.org
American Cancer Society Cancer Action Network Inc ...................... www.aicr.org
Cancer Legal Resource Center: www.disabilityrightslegalcenter.org/cancer-legal-resource-center
Firefighter Cancer Support Network ........................................... www.firefightercancersupport.org
Foundation for Health Coverage Education ................................ www.coverageforall.org
Friend for Life Cancer Support Network ....................................... www.friendlylife.org
The Gathering Place A Caring Community for Those Touched by Cancer ........................................ www.touchedbycancer.org
Gems of Hope Inc. ........................................................................ www.gemsofhope.com
Health Connections Network ..................................................... www.healthconnectionsnetwork.org
LIVESTRONG Foundation ........................................................... www.livestrong.org
Living Well Cancer Resource Center .......................................... www.livingwellcancer.org
The Mautner Project ..................................................................... www.whitman-walker.org/mautnerproject
National Coalition for Cancer Survivorship ................................ www.cancerandsurvivorship.org
Office of Cancer Survivorship .................................................... http://cancercontrol.cancer.gov/ocs
Patient Advocate Foundation ..................................................... www.patientadvocate.org
Research Advocacy Network ..................................................... www.researchadvocacy.org
Triage Cancer ................................................................................ www.triagecancer.org
Vital Options International and The Group Room Interviews and Advocacy in Action Videos ........................................ www.vitaloptions.org

RESEARCH
American Association for Cancer Research ...................................... www.aacr.org
American Institute for Cancer Research ......................................... www.aicr.org
Cancer Research Institute ............................................................. www.cancerresearch.org
The Chemotherapy Foundation .................................................... www.chemotherapyfoundation.org
Friends of Cancer Research ......................................................... www.focr.org
International Cancer Advocacy Network ...................................... www.askican.org/cancerresources
International Cancer Alliance for Research and Education ............ www.icare.org
Pire Street Foundation ................................................................. www.pirestreetfoundation.org
Prevent Cancer Foundation ........................................................... www.preventcancer.org
Research Advocacy Network ..................................................... www.researchadvocacy.org
Scott Hamilton CARES Initiative ................................................ www.scottcancercare.org

VETERANS’ ASSISTANCE
CancerCare .................................................................................. www.cancercare.org
Family Caregiver Alliance ............................................................ www.familycaregiver.org
Fisher House ................................................................................ www.fisherhouse.org
National Hospice and Palliative Care Organization ....................... www.nhpco.org
U.S. Pain Foundation ..................................................................... http://uspainfoundation.org

THE ADVOCACY CONNECTOR
A Powerful Resource for Patients

The Advocacy Connector is a dedicated, up-to-date resource that connects patients with national and state organizations offering assistance.