CANCER SURVIVORSHIP
A GUIDE FOR PATIENTS AND THEIR FAMILIES
Third Edition

Where information equals hope

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Global Resource for Advancing Cancer Education

CONTENT REVIEWED BY A DISTINGUISHED MEDICAL ADVISORY BOARD
“When life and death are on the line, your geography should not matter. Everyone should be able to get the same information about their disease regardless of where they live.”

Laya Bogatchchi
Board Member & Cancer Caregiver

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A “survivor” is generally defined as a person who continues to function, prosper and cope well with life’s difficulties. As a “cancer survivor,” you realize the meaning takes on an even greater purpose. You have made it through active treatment and adjusted your life in many ways — personally, professionally, physically and emotionally. Not only have you demonstrated the strength and will to survive, you are working hard to get the most out of your life. You now define “survivor”.

As you transition from active treatment to post treatment, you may find that returning to the way life used to be may be difficult. The first few months will be a time of change — from your finances and eating habits to your emotional well-being. Give yourself time to adapt to these changes. Planning, knowing the available resources and learning how other survivors have handled this next step will help.

Defining cancer survivorship
A common definition of cancer survivorship includes people who are living with, through and beyond cancer. This includes those who are living cancer-free and those who are continuing cancer treatment as a chronic condition. For the purpose of this guide, the terms “survivor” and “survivorship” are meant to be used in reference to individuals who have moved past the initial treatment phase.

Survivorship statistics
Cancer statistics are important for understanding how cancer affects the population and for assessing the success in society’s ability to manage the disease. According to the American Cancer Society, as of January 2016, there are a million more cancer survivors than the previous year, with more than 15.5 million cancer survivors in the U.S.; 67 percent of those survivors are five years or more beyond their original diagnosis, with 17 percent diagnosed 20 or more years before. Advances in early detection and treatment, and improvements in side effect management, can be credited with increasing survival rates.

What to expect
Issues related to cancer and its treatments are not always resolved when treatment ends, and it can take time to recover. Recovery – both physical and mental – takes a great amount of patience, as your body may feel the aftermath long after treatment has ended. Side effects, such as fatigue, chronic pain or cognitive dysfunction (“chemo brain”), could last days, months or even years. You may also experience changes in mood or emotions that can range from joy and relief to anxiety and fear.

There are many ways to alleviate and manage these effects and moods, so maintaining an open dialogue with your health care team even after treatment ends is vital. Your quality of life after cancer should be a continuing, lifelong focus as you move forward.

Many national advocacy groups suggest survivorship plans to help ease the transition from active treatment to post treatment. Each person has a different story, and your experiences may be unlike any others. As you write this next chapter, remember that there are resources available to help.

ADDITIONAL RESOURCES
- American Society of Clinical Oncology: www.cancer.net/AAboutSurvivorship
- Global Resource for Advancing Cancer Education (GRACE): www.cancergrace.org
- Journey Forward: www.journeyforward.org/SurvivorshipCarePlan
- National Cancer Institute: www.cancer.gov/Survivorship
You will need to monitor your health for the rest of your life, and to do that, you need a plan. Similar to the way your treatment plan helped you navigate treatment, a survivorship care plan can help you stay healthy as you move forward.

Your survivorship care plan should include everything from your medical history and the treatment(s) you underwent to a follow-up care schedule and more. A Survivorship Diagnosis Care Summary is included on page 5 to help guide you. You can download or make copies of it to use as you create your plan.

Following are the key elements of a survivorship plan. Be sure to thoroughly discuss each component of your survivorship plan with your oncologist. In addition, it is important to share this information with your primary care physician.

Medical history
The security of an up-to-date medical history record that has been thoroughly detailed and well-maintained will aid any future doctors in providing you with superior health care. Your records should contain a complete history of your cancer diagnosis, along with other disorders and diseases you may have or had, and a history of your medical care, including test results, treatments and procedures, side effects, dates, etc. Your records should also include information such as immunizations and vaccinations, dental records, your past and current prescriptions and over-the-counter medications, allergies and sensitivities, injuries, nutritional habits, pain issues and ongoing health problems.

Diagnosis
In addition to your medical history, your survivorship care plan should accurately reflect your exact diagnosis, including the date of diagnosis, the specific tumor type, the stage and/or grade of the tumor, the location of the tumor, 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, document that information as well.

Health care team
If you haven't already, create a contact list for your entire health care team now. Include their names, titles, phone numbers and addresses, and describe each person's role in your care. You may think you'd never forget any of this information, but as the years pass, you could. It's important to document this information so that if 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 treatments in your survivorship plan can help ensure you get the best care in the future. Ideally, you already have written records of all your treatments. However, if you didn't track this information, ask your doctor to help you create a treatment plan summary. Include all of the following details that apply.

- 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
- Drug therapies – drug names, dosages and types, as well as administration dates and duration

It's also important to include information about your family's cancer and overall medical history. Certain types of cancer, such as breast, colon, melanoma, ovarian and prostate, have a hereditary link, which means they may be more common in some families than others. This can 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 (hereditary cancer).

If your family has a history with cancer, your doctor may recommend genetic testing to look for gene mutations (changes). Certain mutations may indicate that you have an increased risk for developing certain diseases. The presence of a mutation does not necessarily mean you will develop cancer — 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 (see Determine if Genetic Testing is Right for You, page 12).

If you do not yet have your family's medical history written down, reach out to your relatives and start compiling a record. It will not only benefit you, it will help your family members, too.
Palliative care – specifics about any symptom management remedies you received, such as antiemetic medication to combat nausea

Other services – specifics about other services you received, such as physical therapy, fertility preservation, advice from a dietitian and counseling

Be sure to 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 and recurrent or second cancers

As you now know, serious illness and its treatment can result in many side effects before, during and after treatment. Late effects are those that appear weeks, months or even years after your treatment ends. Your survivorship plan should include information about your risk for developing various late effects based on your specific diagnosis and treatment plan. Be sure to ask your doctor about the signs and symptoms to watch for so you can begin to manage these late effects before they become serious.

In addition, your survivorship plan should include information about the risk that your disease may come back (recur) as well as your risk for developing a new type of cancer (second cancer) or related disease (see Monitoring for Recurrent and Second Cancers, page 11). It’s important to be aware of these possibilities so you can monitor your health and identify any signs as early as possible.

Follow-up care schedule

At the end of your treatment period, your doctor should have discussed your follow-up care schedule. This details the need for future appointments, lab work, scans and/or any ongoing maintenance therapy.

Adherence

Your survivorship care plan is only useful if you actually understand and use it. If you have questions about any parts of your plan, don’t hesitate to ask your doctor. Also, continue to update your plan as necessary and make a few copies of it to tuck them away for your doctors in the future.

Survivorship life plan

When you think about it, this care plan is really your survivorship LIFE plan. It launches you on a course of wellness and empowerment, and keeps you on track for being and remaining healthy as you move forward with your life as a survivor.

ADDITIONAL RESOURCES

- American Cancer Society: www.cancer.org Survivorship Care Plans
- Global Resource for Advancing Cancer Education (GRACE): www.cancergrace.org
- National Cancer Institute: www.cancer.gov Facing Forward: Life After Cancer Treatment
- National Coalition for Cancer Survivorship: www.canceradvocacy.org Living Beyond Cancer

A HOLISTIC APPROACH TO WELLNESS

Now that you are equipped with a survivorship plan, it is important to focus on how to lead a healthy lifestyle. Your treatment likely took more than just a physical toll, and you may already be struggling with a variety of challenges as you transition to life after treatment. Managing these struggles and creating a successful lifestyle roadmap requires attention to and consideration for all aspects of your life — from your eating habits to your emotional well-being.

Following are some areas in which survivors commonly experience challenges.

EMOTIONS

Treating a serious illness can affect the mind as well as the body. Even after treatment ends, you may experience stress, depression, anxiety, guilt and fear. Fortunately, resources are available to help you manage these feelings. Talk to your medical team for assistance with this.

HEALTHY HABITS

Staying healthy and active may be just as important as sticking to your follow-up schedule. This includes good nutrition, physical activity as you are able, and following good health habits. While there are some general nutrition guidelines everyone can follow, healthy eating is slightly different for every survivor. Talk to your doctor or ask for a referral to a dietitian to discover the healthiest eating habits for you. Also, ask your doctor to outline an exercise regimen that you can follow. Unless you continued to exercise during treatment, you will likely need to start slowly and gradually build up your strength and endurance.

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 include information about programs designed to help you quit. You might also set a limit on your weekly alcohol consumption or commit to wearing sunscreen every time you go outside.

SPIRITUALITY

Making sense of your experiences can be challenging. It is natural and normal to wonder “Why me?” You may not know how best to move forward. Some people find meaning and purpose through their faith or religion. Others may question their beliefs. Regardless of your religious practices, your overall quality of life can improve if you develop peace of mind and a sense of meaning.

FINANCES

Many people struggle with the expenses of treatment. Financial assistance resources are available to help you manage this burden (see page 25). And remember, it is essential to maintain dependable health insurance going forward.

HOW TO CONTRIBUTE

As a survivor, you possess information and experiences that can be used to help other people in similar situations. You have the ability to improve the lives of others through advocacy, communication, education and fundraising.
**SURVIVORSHIP DIAGNOSIS CARE SUMMARY**

*Use this to document important information* regarding your medical care. Make copies and update it as your condition changes. **NOTE:** This is not meant to replace your permanent medical records.

### YOUR DIAGNOSIS

<table>
<thead>
<tr>
<th>CANCER TYPE / SUBTYPE / LOCATION</th>
<th>STAGE / GRADE</th>
<th>DIAGNOSIS DATE (YEAR)</th>
<th>FAMILY HISTORY OF CANCER</th>
<th>GENETIC MARKERS (if any)</th>
</tr>
</thead>
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### YOUR TREATMENT RECORD

**SURGERY:**

<table>
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<tr>
<th>TYPE OF PROCEDURE</th>
<th>BODY AREA TREATED</th>
<th>DATE</th>
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**RADIATION THERAPY:**

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<tr>
<th>TYPE (brachytherapy, external-beam radiation therapy, systemic radiation therapy)</th>
<th>BODY AREA TREATED</th>
<th>HOW OFTEN</th>
<th>START AND/OR END DATES</th>
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**DRUG THERAPY:**

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<th>TYPE (chemotherapy, hormone therapy, immunotherapy, targeted therapy)</th>
<th>DRUG</th>
<th>ORAL/IV</th>
<th>DOSE</th>
<th>HOW OFTEN</th>
<th>START AND/OR END DATES</th>
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### YOUR TREATMENT TEAM

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<th>NAME</th>
<th>TITLE</th>
<th>CONTACT INFORMATION</th>
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### Symptoms or late effects that have continued or occurred after the end of treatment:

- Anemia (low red blood cell count)
- Changes in appetite
- Cognitive dysfunction (“chemo brain”)
- Depression
- Fatigue
- Heart issues
- Lymphedema (fluid buildup and swelling)
- Menopausal symptoms
- Neuropathy (tingling, numbness or pain in hands/feet)
- Neutropenia (low white blood cell count)
- Pain
- Sexual difficulties
- Skin problems
- Stress or anxiety
- Weight gain or loss

For additional copies of this form, go to PatientResource.com/SurvivorshipPlan.pdf
**FOLLOW-UP CARE PLAN**

*Even though you have completed* your primary treatment, there are still many steps to take to continue to monitor your health. These steps are part of your follow-up care plan. Like treatment plans, follow-up care plans vary and change over time. Your doctor designed your follow-up care plan using the specific details of your diagnosis and treatment. Use the grid below to record your progress as you follow your plan.

<table>
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<tr>
<th>CONSULTATION TYPE</th>
<th>APPOINTMENT DATE/TIME</th>
<th>WHEN TO SCHEDULE</th>
<th>PHYSICIAN</th>
<th>LOCATION</th>
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You may continue with “maintenance” cancer therapy. If this is part of your follow-up plan, use the grid below to manage it.

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<tr>
<th>TREATMENT TYPE</th>
<th>REASON</th>
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Continued visits with your primary care physician are critical components of both your general health and post-treatment care. Talk to your doctor if you experience any of the following:
- A new symptom
- A symptom that does not go away or becomes worse
- A symptom that may be related to the return of cancer

Make a list of symptoms that will require you to call your doctor immediately:

__________________________________________

__________________________________________

__________________________________________

Make note of the late effects or long-term effects associated with your particular diagnosis/treatment:

__________________________________________

__________________________________________

**Consider any concerns you may have as you transition into survivorship, and discuss them with your health care team.**

- Chronic pain
- Emotional health
- Fatigue
- Fertility
- Financial assistance
- Insurance
- Memory confusion
- Nutrition and weight changes
- Parenting skills
- Physical and muscle control
- Returning to school
- Sexual health
- Stopping smoking
- Transitioning back to work
- Other: ________________________________

*For additional copies of this form, go to [PatientResource.com/SurvivorshipPlan.pdf](http://PatientResource.com/SurvivorshipPlan.pdf)*
these days when people ask me how I’m doing, I tell them, “Better than I deserve.” I’m happy, healthy and successful. In fact, a prominent business magazine in Kansas City named me one of the top 50 people you should know in the state of Missouri.

As a cancer survivor, I encourage you to not let the strength you found during your cancer diagnosis and treatment dwindle. It is important that you continue to be aware of your body and of your health. You are your own best advocate, and being proactive will allow you to continue to thrive as you survive.

My cancer experience began when I discovered an unusual lump in my left breast during a self-exam. I was diagnosed with, battled and beat Stage IIIA infiltrating (invasive) ductal carcinoma that was both estrogen receptor- and progesterone receptor-positive. Early in the process, I decided I didn’t want to keep my disease a secret; so soon after my diagnosis, I publicly revealed I had cancer on a local talk radio station.

You see, I’ve been a real estate agent in the same area for about three decades, so I’ve developed a very visible reputation in my community. I have a time blocked every week on the radio station to chat about real estate, but for that one week, the topic was drastically different. Instead of discussing new listings and mortgage rates, I told the story of an incredibly strong woman who was on the brink of beating breast cancer. At the end of the story, I revealed that the woman was me.

After undergoing a double mastectomy, chemotherapy and radiation therapy, I came out victorious. Now, I’m thankful that my cancer is behind me, and I’m also thankful my disease and treatment didn’t leave me with any long-term physical side effects.

Emotionally, a few things linger. Most of the time, it’s as if the cancer was never there, but in the back of my mind I can’t help but wonder if it’s going to come back someday. I still get a little anxious every time I have my follow-up blood tests, but I’ve passed the critical five-year mark and, so far, everything’s good. I thank God every morning for my continued survival.

Bobbi Bash was diagnosed with breast cancer at 59 and is now a breast cancer survivor. But more than a survivor, she is an educator who has made it her mission to use her locally well-known persona as a real estate agent to spread awareness about the disease. She has three adult children – two daughters and one son – and seven grandchildren. She also enjoys the company of her dog.

I don’t consider my relationship with cancer over. I continue to make myself publicly available to discuss breast cancer with anyone who’s interested. During such conversations, I stress the critical importance of self-exams and advocate for double mastectomies because I believe those two procedures saved my life. I use my platform in society to market for breast cancer awareness and to promote mammograms and regular checkups. In addition, every October I take out a full-page breast cancer awareness ad in all the local papers. In my opinion, it’s important to continue to keep this disease at the top of people’s minds.

My daughter Suzanne began volunteering with the Susan G. Komen charity after my diagnosis, and she is now the “Race for the Cure” program manager. She dedicates her life to supporting patients and survivors, and strives towards the goal of finding a cure for cancer. Together, we have participated in “Race for the Cure” fundraiser events and the Susan G. Komen “3-Day,” a 60-mile walk to help raise awareness for breast cancer.

I was on my way home from visiting Suzanne in Florida when I generated the idea for my “Wear Pink Wigs” campaign. While at the airport, I saw a woman wearing a pink wig, and I thought to myself, “What a cool idea!” When I got home, I started doing some research and found a website that carries pink wigs for about $10 each. The next day, I went around and started getting people to buy these pink wigs. I also started promoting the mission during my weekly radio spot.

By the time October came around, I had more than 300 people in my community who had purchased and were committed to wearing pink wigs for a week. I’m still amazed at how many businesses participated. From banks and grocery stores to passionate individuals, the community really rallied around my idea. The “Wear Pink Wigs” campaign was a success and continues to grow and reach more people with each passing year.

My advice is just keep fighting — fight for yourself and fight for others going through what you’ve already conquered. If you can be of help to anyone else, be sure to reach out to them. You’ll forever be a part of a cancer community, and that community can tremendously benefit from the wisdom you’ve acquired. Find a way to give back that means something to you. The outward support you’ll receive and the inner peace you’ll find will be unparalleled.
When treatment ends, some survivors are able to close that particular chapter of their lives. They readjust to a new normal and, for the most part, don’t experience any major health issues related to their experience with the disease. Others, however, experience side effects of treatment that last beyond the end of their therapy regimen. These are known as “late effects.”

Chemotherapy, hormone therapy, immunotherapy and targeted therapy are systemic therapies, which mean, in most cases, the drugs travel through the entire body in the bloodstream. Late effects from these treatments depend on the particular drug and how your body reacts to it. Other treatment types, such as surgery and radiation therapy, generally only cause late effects in the region that was treated. For example, if your treatment involved radiation to the head and neck, you might experience dental issues that wouldn’t affect someone who had radiation to the pelvis.

Late effects are notoriously hard to predict. Some effects may simply go away over time; others may be permanent. Some might even appear a few years later without warning. They also vary from person to person and often depend on the type of treatment and the length of time it was given, as well as the individual’s age, gender and overall health.

Ask your doctor or other members of your health care team about possible late effects you may experience based on the types of cancer treatments you had. Although you aren’t able to prevent late effects, you can take certain steps to improve your health and lifestyle that will prepare you to better handle any health issues you may experience in the years to come (see Importance of Healthy Eating and Exercise, page 22). Like almost all side effects, most late effects can be treated more easily the earlier they’re detected. That’s why it’s so important to stay in contact with your doctor to communicate any new health concerns.

Following are some of the most commonly experienced late effects and suggestions on how you may manage them.

**Bone loss**

Many cancer treatments, including chemotherapy, hormone therapy and radiation therapy, as well as medications, can cause loss of bone mass. The loss of bone density occurs when the cells that rebuild bone are not replaced as fast as they get destroyed. As a result, bones become thin, porous and brittle. Once bone is lost, it cannot be replaced. Bone loss also occurs if a person has bone metastasis (spread of cancer to the bone).

Bone mass can be measured with a bone density scan before treatment so that your doctor can compare the results to scans taken during and after treatment. This is different than a bone scan that is designed to look for cancer within the bones. Your doctor may prescribe medications or recommend external-beam radiation therapy to relieve symptoms of bone loss. When multiple sites of painful bone metastases exist, a substance with a low level of radioactive material can be injected into a vein to relieve pain.

**Tips to try:**

- Get enough calcium by eating dairy products, leafy greens and beans. Get enough vitamin D3 by eating salmon or fortified breakfast cereal. With your doctor’s approval, take supplements to ensure you get plenty of both.
- Get your vitamin D3 level checked in your blood before starting treatments. Your number should be 30 or above.
- Maintain a healthy weight to prevent bone loss and fractures (breaks).
- Power walk for 30 minutes three to five times a week.
- Wear shoes that fit well, and eliminate clutter in your home to avoid falls.
- If possible, exercise daily to help stimulate bone-forming cells.

**Cognitive dysfunction ("chemo brain")**

People being treated for cancer may refer to “chemo brain” when they can’t think clearly or have trouble remembering details, such as names and dates. Cognitive dysfunction is associated with chemotherapy, but it can occur in people receiving many types of treatments. Although cognitive dysfunction is treatment-related, some people don’t experience it until months or even years after treatment ends. It has also been linked to post-traumatic stress disorder.

**Tips to try:**

- Use a daily planner to keep track of events and appointments. Make a list each day of things to do. As you complete each task, draw a line through it and go on to the next task.
- Solve crossword puzzles or number games to strengthen your mental ability.
- Track memory and attention problems to determine when you’re most affected.
- Don’t multitask; instead, focus on one thing at a time.
- Practice mindfulness and yoga for 15 to 30 minutes a day.
- Let friends and family know you’re having trouble remembering things, and ask them to help you by repeating information.

**Fatigue**

Fatigue, or feeling physically exhausted, is one of the most common side effects people experience, and it continues long beyond treatment for about 30 percent of cancer survivors. In fact, the American Society of Clinical Oncology issued a guideline that recommends routine screenings for fatigue, even after patients complete their primary treatment. Treatment-related fatigue occurs primarily because the body needs extra energy to repair the healthy tissues damaged by cancer treatment. Different from the fatigue that healthy individuals feel, this type of
fatigue usually lasts longer, is more severe and is unrelieved by sleep. Fatigue is treatable, though, and managing your fatigue is an essential part of your health care.

**Tips to try:**
- If possible, perform regular exercise, such as walking or yoga. Power walking for 30 minutes a day, five days a week has been proven to reduce fatigue caused by radiation by 71 percent.
- Get eight hours of sleep at night. Take frequent naps, and limit them to no more than 45 minutes.
- Save your energy for activities that are most important to you.
- Eat a healthy diet to help promote healing and restore your energy.
- Seek relief for other symptoms that may contribute to fatigue, such as nausea, vomiting and depression.

**Infertility**
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 therapy are known to damage 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.

**Tips to try:**
- If you haven’t been evaluated since treatment ended, ask your doctor about testing to see if your fertility was affected.
- Explore other options for parenthood, including adoption or the use of an egg, embryo or sperm donor.

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**Lymphedema (Swelling)**
Your lymphatic system carries white blood cells throughout the body to fight infections. When lymph nodes are removed by surgery or damaged by radiation therapy, infection or the cancer itself, lymph can build up, which can cause swelling in the area where the lymph nodes were removed, including the arms, legs, face, neck, abdomen and genitals. Along with swelling, the part of your body that is affected may feel tight or hard, and you may notice tingling, a lack of flexibility or discomfort. When lymphedema occurs months or years after cancer treatment, it is referred to as chronic lymphedema.

**Tips to try:**
- Wear loose clothing or jewelry on the affected side, and carry your handbag or briefcase on the unaffected side.
- Wear compression garments or tight bandages designed to apply pressure to the swollen area that have been specifically prescribed and fitted for you by a certified lymphedema therapist.
- Elevate the swollen limb.
- Ask your medical team to refer you to a certified therapist trained in ways to manage lymphedema, such as manual lymphatic drainage or complete decongestive therapy.

**Neuropathy**
Neuropathy is pain or discomfort caused by damage to the peripheral nervous system, which includes the nerves that control movement and feeling in the arms and legs. Symptoms include numbness, pain,
burning, tingling or loss of feeling in the hands or feet. Many types of
treatment can cause neuropathy. If you are taking a medication that
is causing neuropathy, your doctor may switch to a different drug,
change how the drug is given or prescribe pain medicines, steroids,
numbing creams or lotions.

**Tips to try:**
- Avoid tight clothes.
- Wear comfortable shoes.
- Keep your hands and feet warm, and avoid standing or walking for a long time.
- Track your symptoms in a journal. Write down when they happen, how long they last and how intense they are so you can share the information with your health care team.
- Ask your doctor for a referral to cancer rehabilitation.
- Ask your doctor for medication designed to minimize severe neuropathy symptoms.

### Neutropenia (low white blood cell count)

Neutropenia occurs when your body doesn’t produce enough neutrophils, a type of white blood cell. Neutropenia puts your body at a higher risk for infection. Nearly half of all people receiving chemotherapy for cancer have neutropenia. If your treatment plan included chemotherapy, your doctor will likely schedule regular blood tests to monitor it. If chemotherapy-related neutropenia occurs with a high fever, or if you have extremely low neutrophil counts, your doctor may prescribe white blood cell growth factors that stimulate the bone marrow to produce more white blood cells.

**Tips to try:**
- Call your doctor if you have a fever. Your doctor will tell you how high your fever needs to be for you to call.
- Wash hands frequently and practice good hygiene to help prevent infections.

### Pain

Diagnostic procedures and treatments may cause different types of pain. After surgery, pain is usually felt in the area of surgery but tends to lessen as the body heals. The pain or discomfort caused by chemotherapy and radiation therapy can be mild to severe and may end when treatment ends. Sometimes, a hormone imbalance or treatment-related nerve damage may contribute to chronic, or persistent, pain.

Common side effects of cancer and cancer treatments, including loss of motion, lymphedema, peripheral neuropathy and osteoporosis, can be other sources of pain.

Untreated pain, even if it’s minor, can get out of hand quickly. That is why it's so important to let your health care team know right away if you're in pain. Some people don’t want to seem as if they're complaining. Others may be fearful that new or worsening pain indicates progression or return of their cancer, which is not necessarily true.

In all cases, though, it is very important that your health care team know what is happening. Reporting pain is the first step to feeling more comfortable and having a good quality of life.

You can help manage your pain by explaining it in detail to a member of your health care team. The more you share about your pain, the better they will be able to help you. Once they understand your pain, they can recommend one or more options for managing it, which may include pain medications, percutaneous pain techniques, targeted drug delivery, neurosurgical procedures and/or rehabilitation care.

**Tips to try:**
- Track when your pain occurs, where it occurs, for how long and if anything makes it better.
- Take pain medications exactly as directed by your doctor. This is known as medication adherence and includes taking the correct dose at specific times.
- Consider integrative therapies, such as guided imagery, yoga, acupuncture and massage therapies.

### Sexuality issues

Cancer and its treatment often affect how people feel about their bodies and how they relate intimately to their partners. Cancer-related sexuality issues are most likely to occur in people who have had treatment directed at their reproductive organs or sexually-related body parts, like a woman’s breasts. A lack of sexual desire and reduced feelings of desirability are common sexual issues for both men and women with cancer. 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 push past the awkwardness and talk to your doctor about any sexual difficulties you’re experiencing (see Reclaiming Your Sexual Health, page 21).

**Tips to try:**
- Attend counseling and/or sex therapy (individual or couples) to help you process the emotions surrounding sexuality issues.
- Exercise to help reduce menopausal symptoms in women and to enhance interest in sex and feelings of desirability.
- Communicate openly with your partner about ways to be intimate other than sexual intercourse.
- Use a vaginal moisturizer daily and personal lubricant during sex to relieve vaginal dryness.
- Ask your doctor about medications for erectile dysfunction.
- Redefine being “sexually active” to finding other ways to express intimacy, in addition to having intercourse.

### ADDITIONAL RESOURCES

- **American Cancer Society:** www.cancer.org Long-Term Side Effects
- **American Society of Clinical Oncology:** www.cancer.net Long-Term Side Effects of Cancer Treatment
- **Pregnancy After Cancer**
- **Global Resource for Advancing Cancer Education (GRACE):** www.cancergrace.org
- **National Cancer Institute:** www.cancer.gov Coping – Late Side Effects

### COMMON LATE EFFECTS BY TREATMENT TYPE

<table>
<thead>
<tr>
<th>CHEMOTHERAPY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone loss</td>
</tr>
<tr>
<td>Cognitive problems</td>
</tr>
<tr>
<td>Constipation</td>
</tr>
<tr>
<td>Diarrhea</td>
</tr>
<tr>
<td>Fatigue</td>
</tr>
<tr>
<td>Fever</td>
</tr>
<tr>
<td>Infertility</td>
</tr>
<tr>
<td>Neuropathy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IMMUNOTHERAPY*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive problems</td>
</tr>
<tr>
<td>Fatigue</td>
</tr>
<tr>
<td>Fever</td>
</tr>
<tr>
<td>Skin reactions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>RADIATION THERAPY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone loss</td>
</tr>
<tr>
<td>Cognitive problems</td>
</tr>
<tr>
<td>Diarrhea</td>
</tr>
<tr>
<td>Fatigue</td>
</tr>
<tr>
<td>Infertility</td>
</tr>
<tr>
<td>Lymphedema</td>
</tr>
<tr>
<td>Skin reactions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SURGERY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive problems</td>
</tr>
<tr>
<td>Fatigue</td>
</tr>
<tr>
<td>Infertility</td>
</tr>
<tr>
<td>Lymphedema</td>
</tr>
<tr>
<td>Pain</td>
</tr>
<tr>
<td>Sexual issues</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TARGETED THERAPY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constipation</td>
</tr>
<tr>
<td>Cough</td>
</tr>
<tr>
<td>Diarrhea</td>
</tr>
<tr>
<td>Fatigue</td>
</tr>
<tr>
<td>Headache</td>
</tr>
<tr>
<td>Shortness of breath or trouble breathing</td>
</tr>
<tr>
<td>Skin reactions</td>
</tr>
</tbody>
</table>

*Because immunotherapy is a relatively new cancer treatment, there is not yet as much information available.

PatientResource.com
Although active cancer treatment is behind you, it is possible the cancer may recur (come back) or that a new type of cancer (second cancer) may develop. Both of these possibilities make it critical for you to stay on top of your health by adhering to your follow-up plan.

Recurrent cancer
When cancer that’s the same type as the original cancer comes back, it’s called recurrent cancer. If you are cancer-free after being treated for a specific type of lung cancer and, a few years later, you are again diagnosed with that same type of lung cancer, that it is recurrent cancer. It can happen weeks, months or even years after treatment stops, and 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 an altogether different area of the body (distant recurrence).

Cancer sometimes comes back because tiny cancer cells occasionally survive treatment and remain in the body undetected. These lingering cells grow and multiply until, eventually, tests can detect them.

Although doctors cannot know for sure who will experience cancer recurrence, they can sometimes make predictions based on the recurrence patterns of certain cancers. Be sure to ask your doctor for more information about your recurrence risk profile.

Second cancer
Like recurrent cancer, a second cancer can develop after you’ve finished treatment for the first cancer. However, unlike recurrent cancer, a second cancer is a different or new type of cancer diagnosis. For example, you are cancer-free after being treated for ovarian cancer and then, a few years later, you are diagnosed with breast cancer.

The breast cancer is considered a second cancer.

Many factors are linked to the development of a second cancer.

- **Cancer treatments.** Leukemia and some solid tumors have been linked to past radiation exposure and past chemotherapy.

- **Cancer types.** Although it’s not yet clear if second cancers are caused by the original cancer or its treatment (or a combination of the two), some primary cancer types are associated with certain second cancers (see Table 1).

- **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 (see Determine if Genetic Testing is Right for You, page 12).

- **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.

The risk for developing a second cancer is small, but it’s still important to talk to your doctor about what to look for and what you can do to help minimize your risk.

Monitoring your health
As a part of your follow-up care plan, your doctor will watch for a potential recurrence or second cancer. Your plan might include physical examinations, blood tests, imaging tests and/or scheduled cancer screenings.

The National Comprehensive Cancer Network recommends certain screening guidelines for most adults by cancer type (see Table 2). However, variations and exceptions to these rules exist, so talk to your doctor about the schedule that’s right for you.

Along with getting screened at the recommended times, you can also be an active participant in monitoring your health. For example, most recurrences of melanoma develop within the first five years of completing treatment.

### TABLE 2
**RECOMMENDED CANCER SCREENING GUIDELINES**

<table>
<thead>
<tr>
<th>CANCER TYPE</th>
<th>SCREENING TEST</th>
<th>AGE</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>Breast self-exam (BSE), Clinical breast exam (CBE)</td>
<td>20+ (women)</td>
<td>40+ (women)</td>
</tr>
<tr>
<td></td>
<td>Mammogram</td>
<td>40+ (women)</td>
<td></td>
</tr>
<tr>
<td>Cervical</td>
<td>Pap test</td>
<td>21 to 29 (women)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pap test + human papillomavirus (HPV) test</td>
<td>30 to 65 (women)</td>
<td></td>
</tr>
<tr>
<td>Colorectal</td>
<td>Colonoscopy</td>
<td>50+ (men and women)</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>Low-dose computed tomography (LDCT) of the chest</td>
<td>55 to 74 (men and women)*</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>Prostate-specific antigen (PSA) blood test with or without a digital rectal exam (DRE)</td>
<td>50 to 70 (men)**</td>
<td></td>
</tr>
</tbody>
</table>

*Lung cancer screening is not recommended in people who are at average risk of lung cancer, but people who meet all of the following criteria may be candidates for screening: in fairly good health, have at least a 30 pack-year smoking history (a pack-year is the number of cigarette packs smoked each day multiplied by the number of years a person has smoked), and are either still smoking or have quit smoking within the past 15 years.

**Men who are African-American or who have a father or brother who was diagnosed with prostate cancer before age 65 should start talking to their doctors about prostate cancer screening at age 45.

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**TABLE 1**
**FIRST AND SECOND CANCERS AMONG ADULT SURVIVORS**

<table>
<thead>
<tr>
<th>PRIMARY CANCER</th>
<th>COMMONLY ASSOCIATED SECOND CANCERS*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bladder</td>
<td>Bladder**, Colon, Lung, Prostate</td>
</tr>
<tr>
<td>Breast</td>
<td>Breast (female, opposite side)**, Colon, Lung, Ovarian, Uterine</td>
</tr>
<tr>
<td>Colon</td>
<td>Bladder, Breast (female), Colorectal**, Lung, Non-Hodgkin Lymphoma, Prostate</td>
</tr>
<tr>
<td>Hodgkin Lymphoma</td>
<td>Acute Non-Lymphocytic Leukemia (ANLL), Breast (female), Colon, Lung, Non-Hodgkin Lymphoma, Prostate</td>
</tr>
<tr>
<td>Testicular</td>
<td>Bladder, Lung, Prostate</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 primary cancer diagnosis in the same organ or site**
after treatment, so your follow-up visits will be more frequent within that time period. However, late recurrence, even after 10 years, is also possible. Your doctor will ask you to participate in your follow-up care with a monthly self-examination of your skin for potential melanoma. During these skin checks, you should also look for any abnormal lumps, especially where the surgery was done, if applicable, and in nearby lymph nodes. The “ABCDE” rule will help you know the difference between melanoma and a mole that is benign (noncancerous) (see Figure 1). Because family history plays an important role in melanoma and other skin cancers, your family members should also have regular skin screenings.

If cancer is detected, your doctor will run various diagnostic tests to learn as much as possible and will then talk with you about your treatment options.

**ADDITIONAL RESOURCES**
- American Cancer Society: [www.cancer.org/SecondCancersinAdults](http://www.cancer.org/SecondCancersinAdults)
- American Society of Clinical Oncology: [www.cancer.net](http://www.cancer.net)
- National Comprehensive Cancer Network: [www.nccn.org](http://www.nccn.org)  
Understanding Your Risk of Developing Secondary Cancers

**FIGURE 1**

<table>
<thead>
<tr>
<th>ABCDE RULE</th>
<th>BENIGN TUMORS</th>
<th>MELANOMAS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A</strong></td>
<td>Asymmetry</td>
<td></td>
</tr>
<tr>
<td>Symmetric</td>
<td></td>
<td>Asymmetric</td>
</tr>
<tr>
<td>(both halves are the same)</td>
<td>(one half is different from the other half)</td>
<td></td>
</tr>
<tr>
<td><strong>B</strong></td>
<td>Border</td>
<td></td>
</tr>
<tr>
<td>Clear-cut, distinct border</td>
<td>Irregular border</td>
<td></td>
</tr>
<tr>
<td>(has notches, is uneven or is blurred)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>C</strong></td>
<td>Color</td>
<td></td>
</tr>
<tr>
<td>Uniform light or dark color</td>
<td>Uneven</td>
<td></td>
</tr>
<tr>
<td>(shades of brown, tan and black)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>Diameter</td>
<td></td>
</tr>
<tr>
<td>Less than 6 mm (usually)</td>
<td>More than 6 mm (about a quarter of an inch)</td>
<td></td>
</tr>
<tr>
<td><strong>E</strong></td>
<td>Evolving</td>
<td></td>
</tr>
<tr>
<td>No change over time</td>
<td>Change in size, shape, surface, shades of color, or symptoms</td>
<td></td>
</tr>
</tbody>
</table>

### COMMON HEREDITARY CANCER SYNDROMES

**Cowden syndrome (PTEN hamartoma tumor syndrome)**
- **Gene:** PTEN
- **Cancer types:** breast, thyroid, uterine

**Familial adenomatous polyposis**
- **Gene:** APC
- **Cancer types:** bone, colorectal, skin, small intestine, stomach, brain tumors

**Hereditary breast cancer and ovarian cancer syndrome**
- **Genes:** BRCA1, BRCA2
- **Cancer types:** breast, pancreatic, prostate, ovarian

**Li-Fraumeni syndrome**
- **Gene:** TP53
- **Cancer types:** adrenal, brain, breast, leukemia, osteosarcoma, soft tissue sarcoma

**Lynch syndrome (hereditary nonpolyposis colorectal cancer)**
- **Genes:** EPCAM, MLH1, MSH2, MSH6, PMS2
- **Cancer types:** brain, breast, colorectal, liver, ovarian, pancreatic, renal pelvis, small intestine, stomach, uterine

**Von Hippel-Lindau syndrome**
- **Gene:** VHL
- **Cancer type:** kidney

### DETERMINE IF GENETIC TESTING IS RIGHT FOR YOU

Although many people who have a family history of cancer worry about hereditary risk, most cancers — even those within a single family — occur simply by chance. In fact, only 5 to 10 percent of cancers are linked to inherited genetic mutations (abnormalities).

However, tests now exist to identify many of the mutations that cause rare inherited cancer syndromes. Geneticists have identified more than 50 of these hereditary cancer syndromes.

Before you decide to be tested, talk to your doctor about genetic counseling, which is recommended both before and after having a genetic test. A genetic counselor can help you make an informed decision about whether to have genetic testing by educating you on the risks and benefits and explaining how testing will affect you and your family.

As someone who has finished cancer treatment, it is important for you to note if other family members are diagnosed with the same cancer in the future. If this occurs, your family will be a candidate for genetic testing. This is important for you and your family members’ doctors to have in the medical records.

Testing is usually requested by a doctor and may be performed on a small sample of fluid or tissue — usually blood, but sometimes saliva, amniotic fluid or a swab of cells from inside your cheek. After being examined at a laboratory, the results are sent back to the doctor and/or genetic counselor or directly to you. At-home or direct-to-consumer genetic tests are available; however, they may detect common genetic variants rather than identifying known hereditary cancer syndromes, and their results may be hard to interpret without the advice of a trained genetic counselor.

Many health care professionals recommend testing only when there is reason to believe a person might have a hereditary cancer syndrome; the test is likely to be expensive, accurate results; or the results are likely to be useful for planning treatment or medical care.

After testing, a genetic counselor can help you to interpret the results and use them to plan future health care. If a genetic mutation is identified, your genetic counselor may discuss options to reduce your risk, including earlier or more frequent screenings, lifestyle changes or preventive treatments. Your doctor may strongly encourage you to share the results of genetic testing with your family. A positive result may confirm a hereditary cancer syndrome and/or indicate a higher chance of a mutation in a first-degree relative (sibling, child or parent). Understanding your results will allow family members to make more informed decisions about their own health care and lifestyle. It’s important to remember, however, that a positive result for a hereditary cancer syndrome does not mean the person who inherits the mutation will get cancer.
Nearly all of the cancer-fighting drugs and treatment methods currently available exist because they were thoroughly tested beforehand. These tests, known as clinical trials, are research studies developed to evaluate different methods of treatment.

Clinical trials may be appropriate for you whether you are currently in treatment or have finished because they study various aspects of cancer. By participating in clinical trials, you may have access to treatments otherwise unavailable. Plus, you’ll contribute to the research necessary to expand cancer care and help others who have a similar disease share the benefits of new discoveries.

Types of clinical trials

Five types of cancer clinical trials exist. Treatment trials are specifically for individuals who have cancer and evaluate whether a new treatment, such as drug therapy, surgery or radiation therapy, or new combinations of treatments, is better than what is currently considered to be the 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 who are experiencing symptoms associated with cancer and cancer treatment. These trials also study the effects of nutrition, group therapy, counseling and other therapies that may help cancer patients and survivors.

The other three types – prevention, screening and diagnostic trials – evaluate and study ways to reduce the chances of getting cancer. Many participants do not have cancer but have in the past and are at risk for recurrence (the cancer returning) or a second cancer (development of a new type of cancer).

Reasons to participate

Many cancer survivors experience short- and long-term effects of cancer and its treatments that may decrease their quality of life or cause additional health problems. Late effects of cancer treatment are side effects that can occur after treatment ends and may include cognitive changes, neuropathy, reproductive complications or pain. There are clinical trials specifically designed to study some of these and other late effects of cancer.

Some clinical studies focus on the effectiveness and safety of certain drug combinations or dosages or the usefulness of different therapies for helping cancer survivors, such as behavioral therapy, exercise and nutrition.

How to find a clinical trial

To find a clinical trial, you can use resources such as the National Cancer Institute (NCI) or the National Institutes of Health (NIH). The NCI offers a searchable online list of more than 12,000 active clinical research trials, and the NIH runs ClinicalTrials.gov, the largest clinical trials database available. You can search studies by cancer type or condition, location or treatment type, or simply by using keywords. You don’t have to wait for your doctor to recommend a clinical trial. You are encouraged to do research on your own and talk with your doctor about participating in one.

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 prior to being accepted for the trial to determine whether you meet all the requirements. The eligibility criteria for 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 of the study 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 doctor visits, hospital stays or certain testing procedures (lab tests, imaging tests). Check with your insurance provider to see if these costs are covered.

Research costs are those directly related to the study, such as the expense of the study drug and testing performed for research purposes, or additional doctor visits. It’s common for the trial sponsor to cover these costs but it’s not guaranteed, and insurance typically does not cover research costs. It’s important to talk to your insurance provider before taking part in a clinical trial.

What to expect if you participate

The clinical trial 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 the trial 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.
Although many survivors may feel a sense of relief or happiness about finishing cancer treatments, you may struggle with how to begin a new chapter in your life without cancer. Survivors often expect life to return to the way it was before they were diagnosed, but many people find, instead, that they are beginning a different life, one that many people refer to as their “new normal.”

Mental and emotional health is an important part of the transition into survivorship. Recovering from serious illness isn’t just about your body; your mind must also heal. It is impossible to predict how survivorship will affect your emotional health because it is different for everyone. But what’s often the same is the shock that occurs when feelings of stress, depression, anxiety, guilt and/or fear – rather than feelings of jubilation and relief – manifest. 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 challenges you may face and knowing when to ask for help are important to your emotional healing.

Following are some common emotional effects that may occur after treatment ends. All of these emotions are valid, understandable and even expected in cancer survivors, but 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 hinder 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 have a qualified employee on staff.

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 begin as soon as your cancer treatment ends and can continue until it is treated. Moderate to severe anxiety is often treated with medication, therapy or a combination of both. The medications most commonly used are antidepressants, anti-anxiety drugs and beta-blockers to control some of the physical symptoms. You may benefit from joining a self-help or support group, where you can express your feelings and share your experiences with others. Stress management techniques, such as meditation, physical activity and deep breathing exercises, can also help lessen anxiety.

If your symptoms are severe, they can interfere with your day-to-day life and even become debilitating. It’s important to seek help if you believe you may be suffering from anxiety.

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
- Social withdrawal
- Repeated episodes of crying

For many cancer survivors, depression is a psychological reaction to the cancer experience as a whole. Certain ongoing treatments or maintenance therapies, such as chemotherapy or hormone therapy, can also cause or contribute to depression. Many cancer survivors 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 (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 can a range of complementary therapies, such as meditation, art therapy, massage therapy, music therapy, writing therapy, exercise and stress-relieving strategies (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.

Many types of antidepressants 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 SSRIs. Another class of drugs, known as psychostimulants, has shown promise in the treatment of depression when given alone or in combination with a different type of antidepressant drug.

Each antidepressant drug has different side effects, which can usually be managed by adjusting the dose or switching the medication. Your doctor will work with you to find the antidepressant that works best with the fewest number of side effects. Antidepressants do not take effect right away and may take several weeks before becoming effective. Be sure to follow the directions for taking your medication exactly as
prescribed by your doctor. Some antidepressants shouldn’t be taken with certain hormone therapy drugs, so ask about potential drug interactions.

Doubt
The sense of doubt that some survivors may feel can lead to confusion and questions about the meaning of life and its purpose. This is common. Some people find strength in support from family, friends, the community or religion. It may help to talk about your feelings with a loved one, close friend, counselor or support group.

Spirituality often refers to how individuals find and express meaning and purpose, and how they connect to everything around them. Your experience with cancer may cause you to look at your faith, religion or spirituality differently. It’s common among survivors and their families to wonder why they got cancer, what it means and how to move forward.

Studies have shown that strong faith and spirituality (regardless of religious practices) are linked to an improved quality of life and being better able to cope with a serious health diagnosis, treatment and survivorship. 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 treatment.

Fear
Many survivors live with the fear that their cancer will return. 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.

Your follow-up visits may involve screening exams and diagnostic tests to monitor for potential cancer recurrence. Even knowing you have an upcoming appointment or scan can trigger fear. This is sometimes referred to as “scanxiety.” It’s normal to feel anxious or overwhelmed just before your next mammogram or CT scan. It may help to take someone with you to your follow-up appointments for support. If you find yourself distracted leading up to your visits, try to avoid making big decisions or tackling important tasks immediately before the appointments.

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. History does not always repeat itself.

Guilt
It’s not unusual for cancer survivors to feel some level of guilt. Some feel they’re to blame for their disease. Others worry that they placed

“The sense of doubt that some survivors may feel can lead to confusion and questions about the meaning of life and its purpose. This is common. Some people find strength in support from family, friends, the community or religion. It may help to talk about your feelings with a loved one, close friend, counselor or support group.”

Lillie D. Shockney, RN, BS, MAS, ONN-CG, is a 25-year breast cancer survivor, as well as a member of the Patient Resource Advisory Board. She holds the positions of University Distinguished Service Professor of Breast Cancer; Director, Johns Hopkins Avon Foundation Breast Center; and Director, Johns Hopkins Survivorship Programs.

“Surviving cancer can bring about a wide range of feelings, many of which can be difficult to express. Writing therapy, also called expressive writing, can help you work through unresolved feelings and reflect on what your cancer experience has meant to you, your family and your friends. According to several studies, writing therapy can even help boost your emotional well-being, reduce your cancer-related symptoms and improve your physical abilities. As a result, cancer centers across the country have started to include expressive writing programs as a complementary therapy option to help people process their diagnoses and cope more effectively. No matter what you choose to write about, never worry about perfection. Right and wrong do not exist in the realm of therapeutic writing, so simply write what you feel. Therapeutic writing can take many forms.”

“Don’t allow cancer to monopolize your mind. You have done what was needed to get rid of it, period. Work on your life goals and add new life goals, now that you have survived this life-altering experience.”
too much of a burden on their loved ones, and some even wonder why they survived while others with similar conditions weren’t as lucky.

If you feel guilty, talk through your feelings with a counselor or therapist to help identify the source of your guilt and teach you how to work through it. Additionally, you might find that you can lessen your guilt by giving back to the cancer community. Helping others can provide a sense of purpose and well-being that can help take away any blame you may be placing on yourself.

**Stress**

Stress is the physical, mental and/or emotional tension that results from an adverse or demanding circumstance, such as cancer. Chronic stress 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, so it’s important to manage your stress before it becomes serious.

It’s common for you to feel stress as you 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 the disease and getting better. Now that you’ve moved beyond treatment, you are faced with transitioning back to the duties and tasks of everyday life, all of which have probably taken a backseat to your health. In addition to realigning to the day-to-day responsibilities, you may face these stresses:

- Finding or keeping a job
- Managing finances and health insurance
- Treating long-term side effects
- Rekindling and maintaining your relationships

**THE REBUILDING PROCESS**

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 is important to share these feelings with your loved ones, not only to develop a clearer picture of the things you want in life but also to help those around you understand, accept and support the decisions you make.

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. Learn to say “no” and take time to simply relax. If, over time, you find you’re unable to adjust to your new routine and your stress levels remain high, it’s important to seek help from a counselor or therapist.

**ADDITIONAL RESOURCES**

- American Cancer Society: [www.cancer.org](http://www.cancer.org)
- American Psychosocial Oncology Society Helpline: 866-276-7443
- American Society of Clinical Oncology: [www.cancer.net](http://www.cancer.net)
- Association of Oncology Social Work: [www.aosw.org](http://www.aosw.org)
- Journey Forward: [www.journeyforward.org](http://www.journeyforward.org)
- LIVESTRONG Cancer Navigation Services: 855-220-7777
- National Cancer Institute: [www.cancer.gov](http://www.cancer.gov)

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**CAREGIVER’S TRANSITION TO POST-TREATMENT**

As a cancer patient transitions into a cancer survivor, your role as a caregiver also changes. You may not be relied upon as heavily as you were when your loved one was undergoing treatment, but you are still an important part of your loved one’s life. You will need to adjust back to a “normal” life, although it won’t be an overnight transition. It may take time for your loved one to be comfortable with his or her new independence. Remember that you and your loved one are still on the same team. Try to be patient with each other and support one another during this time of transition.

Adjusting to life after being a caregiver to someone in active treatment may be very emotional for you. You may become depressed. Recent studies have shown that caregivers are at an increased risk for developing depression, a disorder consisting primarily of a depressed mood and a loss of interest or pleasure in normal activities (see *Navigating the Emotional Effects of Survivorship*, page 14). It is more than just feeling sad or blue. Depression can occur at any time throughout the caregiving journey and can be brought on by stress and its effects on your personal life and emotions. If you experience any of the symptoms of depression, it is important to seek help from your doctor or counselor. You may also consider exploring online support groups and other resources.

Once a loved one no longer needs as much assistance, you may experience exhaustion, also known as fatigue or burnout. This type of exhaustion can be physical, emotional and/or mental. Sometimes, when you’re no longer keeping up the incredible pace that has become normal for you as a caregiver, your body finally lets down its guard and all of the symptoms you’ve been holding back come surging forward. This can also happen if you’ve neglected yourself while caring for a loved one. Sometimes, the exhaustion leads to a physical illness, such as catching a cold or triggering an existing autoimmune disorder.

Take time to rest and return to hobbies you may have stopped. Re-establish relationships with family members, friends or co-workers that were put on hold while you were caregiving, and develop or increase healthy habits, such as exercising and eating healthy foods.

You may also experience the same fear your loved one has about cancer returning. No one can predict if your loved one will develop cancer again, but you can manage your concerns by researching the type of cancer your loved one had and the possibility that the cancer may return. That likelihood will depend on the type and stage of cancer and how well the treatment worked. Some cancers are more prone to recurring (coming back) than others. To get more information, discuss your concerns with your loved one’s doctor.

Another fear that may develop post-treatment is the anxiety (worry) that accompanies upcoming scans, which is sometimes referred to as “scanxiety.” Anticipating the day of the scan or the results can be just as scary for the caregiver as the survivor. Take deep breaths, try to relax and consider sharing your feelings with a friend.
The first sign that something was wrong occurred when I was 26 and helping a friend move before Christmas. All of a sudden, it felt like the wind got knocked out of me. I tried to pick up a box and simply couldn’t. The next morning, one of my testicles was slightly enlarged, but I wasn’t too concerned. By Christmas, it was larger and seemed to be growing rapidly. My doctor referred me to an urologist, and after an ultrasound, he told me I had a tumor in one of my testicles that needed to be removed as soon as possible.

The surgeon removed the entire testicle. The biopsy results came back as malignant. I was diagnosed with Stage II nonseminoma testicular cancer that had spread to my lymph nodes and chest. I had a second surgery to remove the affected lymph nodes, and my doctor put me on a nine-week chemotherapy regimen. The treatment was one of the most difficult things I’ve ever gone through, but I survived and am now cancer-free.

When you go through something like cancer, you look at life differently. When I was diagnosed, I was a hard-charging sales guy and let nothing get in my way. Now I think about what is really important in life. I’ve become more spiritual since I’ve become a survivor. I believe in karma, seeing the glass as half full and doing unto others as you would have them do unto you. I look at the bigger picture now. I’m an eternal optimist.

I was a bit of a late bloomer in life. I didn’t marry until I was 39 and didn’t have children until I was 44. Now that I have two beautiful children and a wonderful wife, I have a new perspective about life. If I were to get cancer again, I wouldn’t hesitate to go through treatment so that I could be there for them. Before I had a family, I thought I’d never go through that again. So, your perspective about life can change as you live your life as a survivor. I look at the bigger picture now. I’m an eternal optimist.

As an eternal optimist, he uses humor and laughter to put others at ease. Today, he is cancer-free and is enjoying life with his wife and two children.

I’ve been able to use my experience to help other friends going through cancer. While I was in college, I was part of a close-knit group of fraternity brothers. Four of us ended up getting diagnosed with testicular cancer. I was the first. One was one of the precious few who died from it. That was so difficult — he left behind a loving wife and a two-year-old daughter. Our fraternity brothers created an annual golf tournament in his memory to raise money to help put his daughter through college. Although I hate golf and would rather watch paint dry, I participated every year to support my friend and his family. It brought all of us back together and was one huge party — the kind of party that he would have enjoyed.

I don’t fear cancer returning. I know I may get some other type of cancer eventually, but I don’t let it affect my daily life. I keep a positive attitude, which is just as important for a survivor as it is when going through treatment.

Although I kept my diagnosis very private while I underwent treatment, as a survivor, I’m now eager to help other men facing a similar situation. I am listed on some support groups for other men to contact about going through testicular cancer and living as a survivor. I’m very open to discussing my experience because it was so helpful for me to have that one-on-one support.

I tell men that if they suspect something is wrong “down there,” get checked out. Testicular cancer is very curable. You never want to take the chance that it is cancer and then wait to get it looked at. When caught early, testicular cancer can be cured. Men need to drop the machismo mindset and realize it’s worth asking your doctor about.

Although I had a testicle removed, I use humor and jokes to help others going through it and to put my friends and family at ease. I’ll use jokes like, “I’m taking my ball and going home,” or “You’re busting my ball.” You have to laugh your way through it all and live life to the fullest.
Like many patients, you may have taken time off from work during treatment and are now exploring the ideas of re-entering the workforce or chasing new life goals. Doing so can be a challenging experience, and it’s one that’s different for everyone. 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.

Mixed emotions are normal, so give yourself plenty of time to work through them. Setting career goals, following a new dream, managing expectations, understanding what you are legally required to tell your employer about your medical condition, determining any necessary modifications you’ll need and seeking support can all help you clear your head and ease the transition.

Goals
Before you jump right back into work, it’s important to re-evaluate your career goals. Do you still want the same things as before your diagnosis, or have your priorities shifted?

It’s also important to re-examine your career abilities. Talk to your doctor about how your follow-up treatment schedule and long-term side effects might affect your ability to perform the same job you had before cancer. Depending on the results of that conversation, you may decide that 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 is less physically 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 the same as it was before your diagnosis. Before returning 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 people may keep their distance and act awkwardly, while others may ask you direct personal questions. Anticipate all possible scenarios and how to react so you’re prepared for that 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 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.

Modifications
Even though you are now outside of your primary treatment, you may be dealing with difficult side effects that might require temporary adjustments at work, such as a flexible schedule, reduced hours, a redesigned workstation, the ability to work from home and/or altered responsibilities. Although your employer is required under the ADA to provide reasonable accommodations, it’s important to not take advantage of that fact and to be fair and upfront about your requests.

Depending on your job, it might be a good idea to talk to your supervisor about your workload. Be realistic about what you can do. Your transition may need to happen slowly, as it can be physically and emotionally tiring. Being prepared may help ease anxiety and any feelings of being overwhelmed. Keep these tips in mind as you prepare to return to school.

Notify the school of expected absences to prevent falling behind. You may need extra time to complete assignments while you are at home or in the hospital.

Ask for simple accommodations to help you ease the transition, such as having extra time between classes to move from one room/building to another, having two sets of textbooks so you can keep one set at home, and being excused from a physical education class.

Look into academic support offered by hospitals to assist you during an extended stay.

Consider visiting the school or campus before returning for classes. Meeting with friends or attending a school-hosted event can help you catch up on the latest news.

If appropriate, meet with an academic advisor to discuss graduation needs and requirements.

If you are a parent sending a child back to school, provide school officials with emergency contact information, including contact information for your child’s oncology team.

Maintain open communication 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.
manage. Work together to reassign duties as needed and to prioritizewhat’s left.

You may find that your energy fades more quickly than it used to. If so, track your energy levels at different times of the day for a couple of weeks. Look for patterns, and then try to schedule your most important work for when you typically feel your best.

Managing your fatigue at work
Some cancer survivors experience long-lasting fatigue. This can make people feel too tired to even eat, and going to or staying at work could be difficult. These tips may help manage fatigue while at work.

- **Take it slow.** Work at a moderate pace to prevent exhaustion. Prioritize. 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 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. 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. 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 dietitian about additional nutrition recommendations that are right for you.

Communication
When you talk to your supervisor – about regular work activities or something related to 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 difficult period, be upfront about it and let your supervisor and colleagues know so they can help pick up the slack. Then, when you bounce back, do what you can to return the favor. In short, the more you communicate, the less stressful your work life will be.

Benefits of returning to work
In addition to adding some financial security, returning to work can bring many benefits:
- Restoring structure to your daily routine
- Providing you with a sense of purpose
- Helping you feel more productive
- Distracting you from health concerns
- Promoting your independence
- Boosting your self-esteem
- Helping you feel connected with others

Support
Don’t assume you must handle this transition on your own. Returning to work is no small feat, so find a counselor with whom you connect or seek a support group where you can talk to people in similar situations. Your company’s benefits package may offer occupational health services. Help is available if you seek it out.

Finding a new job
Your health history shouldn’t affect your ability to get a job, but you may need to adjust and/or rehearse a few things before sending résumés and going to interviews.

- **Reformat your résumé.** If your treatment caused significant gaps in your employment history, you may want to deviate from the standard chronological format in favor of a functional format. Functional résumés highlight job skills and qualifications first, rather than leading with employment history. If your résumé includes dates, you may also want to omit the months and include only the years, or simply list the number of years of service. This allows you to be discreet while still remaining truthful.
- **Rehearse your responses.** Although 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.

Employment discrimination
If you feel your cancer history is causing your employer to discriminate against you, contact a social worker or legal agency and seek help. Remember, you have rights in the workplace.

- **Accommodations.** Under the ADA, you are qualified for your job – and your employer must consider you so – as long as you can successfully perform your job functions with reasonable accommodations.
- **Safety.** When it comes to concern for safety, your employer may exclude you from a task only if it poses a direct threat of substantial harm to you or others that a reasonable accommodation cannot eliminate. You may not be excluded for safety reasons based on a hunch, fear or stereotype about cancer.
- **Harassment.** Just as other laws prohibit harassment based on race, sex, color, national origin, religion, age and genetic information, the ADA prohibits harassment or offensive conduct based on disability.

ADDITIONAL RESOURCES
- American Cancer Society: www.cancer.org
- American Society for Clinical Oncology: www.cancer.net
- Cancer and School
- Cancer and Careers: www.cancerandcareers.org
- Cancer for College: www.cancerforcollege.org
- National Coalition for Cancer Survivorship: www.canceradvocacy.org
- Patient Advocate Foundation: www.patientadvocate.org

"Kathryn M. is a pseudonym used to protect her privacy."
When you were first diagnosed, you likely turned your primary energy to fighting the cancer and trying not to worry too much about the cost; however, it is difficult not to be overwhelmed by the financial costs associated with treatment. Unfortunately, the financial aspect of cancer can have a huge effect on your overall health, happiness and well-being during and after cancer treatment — most times well into survivorship.

Even people with good health insurance coverage may have difficulty affording treatments and other non-treatment-related costs. These include direct medical costs, non-medical costs, such as transportation, child care, lost time from work and daily living expenses, that can become a burden during treatment. You can also expect some ongoing costs for follow-up care appointments once treatment ends and you are being monitored as a survivor.

As some of these bills add up, you may find that you need assistance. Many organizations and resources are available that can provide help with covering these costs. See the resource section on page 25 for a list of groups you can consider reaching out to if the need arises.

Types of cancer-related costs
The cost of treating cancer is different for every person. The expenses you had depended on your diagnosis, your recommended treatment plan, your follow-up care and your level of insurance coverage. A recent study found that nearly one-third of cancer survivors experienced financial difficulties after being diagnosed and treated. A financial difficulty was defined as borrowing money, declaring bankruptcy, worrying about paying medical bills, being unable to pay for medical visits or making financial sacrifices.

Unfortunately, a study found that cancer survivors spend between $3,000 and $4,000 more annually than their healthy peers who have never had cancer. These extra expenses are attributed to the follow-up care and ongoing screenings needed to ensure health.

Cancer-related costs can add up quickly, so it’s vital to talk to the members of your health care team about the cost of your cancer care as soon as possible. They understand that treatment can be expensive and may create financial hardship, so don’t be embarrassed to bring it up. Be sure to talk to the financial staff/counselors at your doctor’s office and at the hospital about your insurance policy and out-of-pocket expenses. Some facilities may be able to arrange a monthly payment schedule or offer you a reduced rate.

Social workers, advocates, financial counselors and patient navigators at your medical facility can also refer you to organizations and charities that may be able to help. Advocacy and nonprofit groups can point you toward sources of assistance. Federal laws offer benefits, protect you from the loss of health insurance and guard against discrimination on the basis of your health. Medicare programs may assist with costs such as monthly premiums, annual deductibles and prescription co-pays. In addition, you may have to adjust to a permanently reduced income if you aren’t able to return to your regular work hours.

Don’t forget your family and friends. They can help you search for financial assistance and offer advice on what would be most helpful for you. They can sometimes be a great resource to help you stay organized, research and gather information, or contact additional resources.

Increasing your knowledge of financial matters, including understanding your insurance, restructuring your budget and seeking assistance, can help you take control of your financial situation.

**ADDITIONAL RESOURCES**
- **American Cancer Society:** [www.cancer.org](http://www.cancer.org)
- **American Society of Clinical Oncology:** [www.cancer.net](http://www.cancer.net)
- **National Cancer Institute:** [www.cancer.gov](http://www.cancer.gov)
- **Study of Cancer and Financial Hardship**
- **Patient Advocate Foundation:** [www.patientadvocate.org](http://www.patientadvocate.org)

**MANAGING PAPERWORK**

- **Being well-organized with your cancer-related paperwork is integral to handling financial matters. Here are three tips for getting started. Remember, the most important thing is that your system is easy for you (and anyone helping you) to use.**
  
  1. **DESIGNATE ONE PLACE** in the house to do all of your paperwork-related tasks. This area should have a desk or table, a chair, a computer and printer (if you plan to pay bills online or store your paperwork electronically), and a filing system. Resist the urge to simply place everything in one file labeled “cancer” or “insurance,” as it will quickly become too large to manage.

  2. **FILE NEW INFORMATION** as soon as you can. That not only reduces the possibility of misplacing something, but it also keeps paperwork from piling up, which can be overwhelming. If you fell behind during active treatment, work to get caught up when feeling better. If you need to, address one financial task per day so it is not overwhelming. When a new bill arrives, be sure to note directly on the bill the date you received it and attach any related papers, such as copies of claims or correspondence about it. Put the bill and attachments in an “Unpaid Bills” folder until you pay it, at which time you can move it to the most appropriate folder. Schedule this work for a time of day that’s best for you, both in terms of your schedule and how you feel.

  3. **CREATE A FILE** for supplemental paperwork, such as a monthly budget worksheet, dates of office visits or diagnostic tests, a list of medications you’re taking, insurance-related correspondence, contact information of all of your health care providers and a list of expenses that are not reimbursed by your insurer.
Both cancer and its treatments can take a significant toll on your sexual health. Sexual activity can benefit you physically, psychologically and emotionally, so it's important for your overall well-being to conquer any problems you're facing. However, reclaiming your sexuality is a process that doesn't happen overnight, so be patient as you work to rediscover this side of yourself.

After going through cancer treatment, many survivors report feeling disconnected from their bodies. An important first step toward reclaiming your sexuality is to embrace your new self, including all the scars, discolrations 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.

Remember, open communication is the key to a healthy intimate relationship. Sit down with your partner and openly share your concerns, fears and other feelings. Allow your partner to respond in kind. Your doctor may also ask if your relationship is negatively impacted emotionally, as sexual health. Estrogen can be given as a flexible ring, cream or tablet.

**Men**

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

- **Medication.** Your doctor might prescribe a medication to help. However, drugs for this may not be appropriate for every man, so be sure to discuss the risks and benefits before taking anything.

- **Secondary treatment options.** If medications aren't effective, your doctor might recommend a penis pump (vacuum erection device). This is a hollow tube with a hand- or battery powered-pump. Using this will create blood flow into the penis, causing an erection. Typically the erection will last long enough to have sex. Other strategies, such as use of penile injection therapy or penile implants, are also options for some men.

**Women**

The most common sexual problems that affect female survivors include vaginal dryness and discomfort, as well as pain during intercourse. Correcting these problems can help boost sex drive, arousal and ability to reach orgasm. Several remedies are available.

- **Dilators.** Vaginal dilators gradually stretch the walls of the vagina, which can help increase vaginal comfort.

- **Low-dose vaginal estrogen.** Estrogen is a hormone that may be used to help improve vaginal health. Estrogen can be given as a flexible ring, cream or tablet.

- **Lubricants.** Water-based vaginal lubricants, which are applied inside the labia, can help reduce pain during intercourse.

- **Moisturizers.** Hormonal creams and non-hormonal, over-the-counter vaginal moisturizers – commonly gels administered as a vaginal suppository or through a tampon-shaped applicator – can help relieve vaginal dryness and painful intercourse when used as directed.

- **Pelvic floor physical therapy.** Some exercises can help relax muscles in the pelvis that may have become tight, weak or tender during treatment. A physical therapist can provide an exercise regimen focused on strengthening the pelvic muscle floor to help reduce pain during intercourse.

**Common post-treatment problems**

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

Emotional side effects, such as depression, anxiety, an altered body image or fear of being viewed as undesirable, can also affect sexual health in a negative way. Your doctor may also ask if your relationship with your partner is tense, strained or in conflict. The emotional impact of being treated for cancer can influence your ability to have sex. Dealing with your feelings and emotions can help treat your sexual challenges.

**ADDITIONAL RESOURCES**

- **American Society for Clinical Oncology:** [www.cancer.net](http://www.cancer.net)
- **CancerCare:** [www.cancercare.org](http://www.cancercare.org)
- **National Cancer Institute:** [www.cancer.gov](http://www.cancer.gov)
- **PearlPoint Cancer Support:**
  - [Sexual Dysfunction](https://my.pearlpoint.org)
  - [Tips for Managing Female Sexual Dysfunction](https://my.pearlpoint.org)
  - [Tips for Managing Male Sexual Dysfunction](https://my.pearlpoint.org)
  - [Dating After a Cancer Diagnosis](https://my.pearlpoint.org)
Living a healthy lifestyle after treatment is just as important as when you were actively being treated for cancer. Although your nutritional needs may change as you move from cancer patient to survivor, eating right and exercising can offer multiple health benefits.

The American Cancer Society recommends that cancer survivors follow the same nutrition guidelines that are recommended to help prevent cancer. Choosing healthy foods appropriate for you will improve your strength and help you feel better.

Making healthy choices

Experts recommend a diet high in vegetables and fruits, whole grains and lean protein. However, after treatment, you may be limited on the types of foods you can eat. Some survivors have permanent lifestyle changes depending on the type of cancer and treatment they had. In general, try to consume fats from beneficial sources, such as olive oil, avocados, nuts and fish, and aim to eat five to nine servings of fruit and vegetables daily. Choose low-fat milk products, such as one-percent or skim milk, and lower-fat cheeses, such as mozzarella. Limit the amount of red meat and processed meat you eat to no more than three to four servings a week. It is also helpful to reduce your consumption of refined sugars. If you drink alcohol, try to limit your consumption to the recommended amounts of one drink per day for women and two drinks per day for men.

Making Exercise and Physical Activity a Priority

Many people have to stop exercising or reduce the time and intensity of their exercise while they are in active treatment. However, experts recommend that survivors return to normal activity as soon as they are able and gradually advance their exercise program to achieve weight and fitness goals. A number of studies show that people with certain cancers who also maintain regular physical activity have a reduced risk of cancer recurrence. Exercise and physical activity are also important in the prevention and treatment of obesity, which may lead to diabetes, heart disease and osteoporosis. Combined with healthy eating, exercise can improve your overall fitness and may lead to a better quality of life.

Many experts recommend that cancer survivors take part in regular physical activity, aiming for 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 after treatment.

A healthy weight

Exercise can help you reach your weight management goals. Some people who start cancer treatment at a healthy weight may experience weight loss or gain from the treatment itself. Because significant weight changes from treatment may lead to a decreased chance of recovery, returning to a healthy weight once treatment ends is important.

Being overweight prior to treatment increases your risk of serious health problems, including high blood pressure, cardiovascular disease, diabetes and certain cancers. During treatment, your priority should be to maintain your weight, but once treatment ends, you should work toward reaching and maintaining a healthy weight.

Movement and strengthening

Your exercise program should include activities to help maintain your muscle strength. These will help prevent loss of muscle mass that may occur from inactivity. Increasing your muscle mass will also raise your metabolism, helping you to burn more fat. Exercises that focus on stretching and flexibility will help your ease of movement and ranges of motion, which may also help you avoid injuries. Lower-body strength exercises can help improve your balance.

Rehabilitation and side effect management

Rebuilding strength and flexibility are important for your recovery and to help prevent further injury. Being physically active can 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.

The effect of exercise on mood and energy

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

Most survivors can get all of the nutrients they need from a healthy, balanced diet. Studies have not found any strong evidence that dietary supplements help in the prevention or treatment of cancer. The National Comprehensive Cancer Network and other experts recommend that cancer survivors only take supplements when recommended by a doctor for a specific deficiency or health condition. Some supplements may be helpful for people who are not able to get or absorb all of the nutrients they need. Talk to your doctor to see if vitamins and supplements are right for you.

Maintaining a healthy weight is important for survivors, especially if treatment caused you to lose or gain weight. Whether trying to lose or gain weight, make sure to eat the essential nutrients, including carbohydrates, fats and protein. You might consider nutritional counseling with a qualified professional, such as a registered dietitian.

If you’re trying to control your weight, it’s important to watch portion size. One serving of meat, fish or poultry is about three to four ounces, which is approximately the size of a deck of cards. 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. 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.
After being treated for cancer, your body may have difficulty absorbing the nutrients you need for optimal health. This can lead to a condition known as malnutrition, or malnourishment. In addition, side effects from treatment may have affected your taste, smell and ability to eat, but these are likely to improve after treatment ends, allowing you to resume eating a healthy diet.

A seemingly endless variety of specialized diet plans, each claiming extraordinary results, is marketed to consumers. Although these diets may include some legitimate approaches with a few proven benefits, beware of any plan that promises a quick fix or ignores basic nutrition. These diets are usually not sustainable over the long term, and you will see longer-lasting results if you shift your overall approach to nutrition.

Dietitians can discuss any restrictions you may have and help you set and reach nutritional 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.

While you focus on gaining strength and feeling good, be aware of other health conditions that may need to be managed in survivorship, including obesity, heart disease and diabetes.

**Obesity**

Poor nutrition may lead to obesity, which has been linked to many cancers, as well as heart disease, diabetes and other diseases. Obesity is a condition in which a person has too much body fat in relation to lean body tissue, and consuming too many calories is among its causes. Although some people expect to lose large amounts of weight during cancer treatment, many discover that they actually added pounds during the process. In fact, about one in three people with breast cancer experiences more than a 5 percent weight gain in the two years after being diagnosed.

Many studies attempt to prove the connection between obesity and cancer. Excess body weight can increase the risk for several other types of cancer due to the effects that fat tissues and fat cells have on the body. The following are risks associated with obesity:

- **Increasing insulin levels and/or hyperinsulinemia (insulin resistance)** may support tumor development.
- Excess estrogen has been linked to breast, uterine and other cancers.
- Chronic low-level inflammation is tied to an increased cancer risk.
- The production of certain hormones may stimulate or inhibit cell growth.
- **Various proteins may influence tumor growth.**

**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.

Although heart disease isn’t a risk factor for cancer, various treatments, including chemotherapy, radiation therapy and hormone therapy, can cause or worsen heart disease. People with heart or vascular conditions before they begin treatment are especially vulnerable. One study showed that women who had radiation to treat breast cancer had an increased risk of heart disease of 3 percent on average.

To combat the increased risk, it’s important for cancer survivors to follow the recommended nutrition guidelines, including limiting the consumption of red and processed meat. Protein can come from many healthy sources, so try to go meatless several days a week, incorporating other protein sources for your meals.

**Diabetes**

Diabetes is a condition in which the body doesn’t make enough insulin, resulting in either high or low levels of blood glucose (sugar). There are two types of diabetes.

- **In Type 1,** 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. It typically arises during childhood and accounts for 5 to 10 percent of all cases of diabetes.

- **In Type 2,** the body either has too little insulin or cannot use insulin effectively. Among the causes of Type 2 diabetes are obesity, high blood pressure and a high-fat and high-carbohydrate diet. This type of diabetes occurs most often in adults and accounts for 90 to 95 percent of all cases of diabetes.

People with diabetes are at a significantly higher risk for many types of cancer, including liver, pancreatic and uterine cancers. A recent study 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, take in regular physical activity and take prescribed insulin and blood sugar medications as recommended by your doctor.

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**WAYS TO ADD NUTRIENTS TO YOUR DIET**

- Choose brightly colored fruits and vegetables rather than colorless starches, such as rice and white potatoes. Use in soups and side dishes.
- Drink juices, milk and premade nutritional beverages instead of soft drinks.
- Look for the words “Excellent source of...” on food packaging, which means the food contains at least 20 percent of the recommended daily amount per serving.

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**GREEN SMOOTHIE**

- 1 large serving
- Makes: 1 large serving or 2 small servings

**Ingredients:**
- 1 cup fresh baby spinach
- ½ cup pineapple chunks or pears
- ½ cup green grapes
- ½ banana
- ½-1 cup of water
- ½-1 cup of ice

**Directions:** Blend all ingredients together.

**Add protein powder if desired.**

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**ADDITIONAL RESOURCES**

- **American Cancer Society:** [www.cancer.org](http://www.cancer.org)
- **American Society of Clinical Oncology:** [www.cancer.net](http://www.cancer.net)
- **National Cancer Institute:** [www.cancer.gov](http://www.cancer.gov)
- **PearlPoint Cancer Support:** [https://my.pearlpoint.org](https://my.pearlpoint.org)
As a cancer survivor, you’re in a unique position to affect other people’s lives in a positive way. Whether or not you realize it, you’ve collected a wealth of information and knowledge throughout your cancer experience that can now be used to help others.

**Types of volunteering**
A wide variety of opportunities to give back exist. If you feel up to it, select one or a few and get involved. Assisting others as they address similar situations to those you experienced will make you feel better and could assist you in your survivorship planning.

**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. Volunteering to lead an in-person or online cancer support group is another option.

**Education**
Cancer and its treatment are foreign concepts to many people, so teaching others about the ins and outs of the disease and the health care world is a huge service. You can teach sessions at a medical facility, community center and/or place of business about a whole host of topics, including specific types of cancer, legal services, health insurance, caregiving, necessary items (wigs and lotions) and much more. Your knowledge will be greatly appreciated.

**Fundraising**
As you well know, cancer treatment can quickly get expensive for individuals, and many cancer-related organizations depend on funding to support their goals. To help, you can organize and/or volunteer at fundraising events, such as races, tournaments, auction events, dinners and more.

No matter how you choose to give back, doing so will not only benefit others, it will also help you meet new people, feel accomplished and continue to heal yourself from the inside out.

**How to find volunteer opportunities**
Volunteer opportunities for survivors are all around — you just have to know where to look. Start by asking your family members, friends and others in your community network whether they know of an individual or organization that could benefit from your help. Or refer to the list of resources available on page 25. 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, advocacy groups and organizations that spark your interest. Ask about their volunteer programs and find out how you can get involved.

**Sharing your story**
Sometimes giving back can be as simple as sharing your personal experience with cancer. A survivor once said, “As survivors, none of us fight alone.” Many patients depend on the survivor community to educate, support and engage them before, during and after treatment. Reach out to your advocacy group of choice to find out if you can share your story with others. If you’re interested in sharing with other readers of Patient Resource guides, email us at editor@patientresource.com.

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**NATIONAL CANCER SURVIVORS DAY SPOTLIGHT**

Each year on the first Sunday in June, survivorship takes center stage as cancer survivors, their friends and family members, and medical professionals around the U.S. celebrate National Cancer Survivors Day. The goal of this inspirational day, themed “A Celebration of Life,” is to increase awareness about the ongoing challenges of cancer survivorship. It’s a chance for everyone who has cancer in their lives to observe the milestones they’ve reached and recognize those who have supported them.

According to the National Cancer Survivors Day Foundation, more than 15.5 million people today are cancer survivors, due in part to advances in cancer prevention, screenings and early detection, and follow-up care. By bringing attention to these positive strides, the National Cancer Survivors Day Foundation hopes to also bring to light the many stumbling blocks that survivors face during and after treatment, such as physical, emotional and economic challenges.

This idea for a survivor rally originally came from Richard and Annette Bloch. The Blochs wanted to bring cancer survivors together to build hope among those facing the disease. The media coverage, before and after the rally, was designed to demonstrate to a much broader audience that a cancer diagnosis isn’t synonymous with death.

The R.A. Bloch Cancer Foundation held the first rally in Kansas City in 1986. Other sponsors soon came aboard and, in 1994, the National Cancer Survivors Day Foundation was formed to equally and fairly assist all cancer-related organizations holding a National Cancer Survivors Day event.

Since then, national and local events have helped promote the need for more resources, research and survivor-friendly legislation to improve the quality of life for cancer survivors. The celebrations typically include guest speakers offering inspiration, advice and updates, along with a variety of merchandise, such as t-shirts, balloons and banners, to help attendees get into the spirit.

If your community doesn’t host a National Cancer Survivors Day celebration, you can take advantage of the leadership opportunity and organize one. The National Cancer Survivors Day Foundation will help you get started. And, don’t worry if you miss this year’s celebration. There are plenty of opportunities year round to promote this worthy cause. Learn how to get involved and find more cancer survivorship resources at www.ncsd.org.
ASSISTANCE & SUPPORT RESOURCES

Cancer Education
American Cancer Society ................................................. www.cancer.org
American Society of Clinical Oncology ......................... www.cancer.net
CANCER101 ............................................................. www.cancer101.org
CancerCare .............................................................. www.cancercare.org
CancerGuide ............................................................. www.cancerguide.org
CancerQuest .............................................................. www.cancerquest.org
Centers for Disease Control and Prevention (CDC) .... www.cdc.gov
The Gathering Place ..................................................... www.touchedbycancer.org
Get Palliative Care ....................................................... www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE) ..................................................... www.cancergrace.org
The Hope Light Foundation ............................................. www.hopelightproject.com
LIVESTRONG Foundation ............................................. www.livestrong.org
National Cancer Institute .............................................. www.cancer.gov
National Comprehensive Cancer Network (NCCN) .... www.nccn.org
National LGBT Cancer Network ..................................... http://cancer-network.org
OncoLink ..................................................................... www.oncolink.org
Patient Power .............................................................. www.patientpower.info
PearlPoint Cancer Support ............................................. https://my.pearlpoint.org
Pine Street Foundation .................................................. www.pinestreetfoundation.org
R.A. Bloch Cancer Foundation .......................................... www.blochcancer.org
Scott Hamilton Cares Foundation ..................................... www.scottcares.org
Triage Cancer ............................................................. www.triagecancer.com

Caregivers & Support
4th Angel Patient & Caregiver Mentoring Program ............ www.4thangel.org
Bloth Cancer Hotline .................................................... 800-433-0464
CanCare ..................................................................... www.canecare.org
CANCER101 ............................................................. www.cancer101.org
Cancer Action ............................................................. www.canceractiontc.org
Cancer and Careers ..................................................... www.cancerandcareers.org
CancerCare .............................................................. www.cancercare.org
Cancer Connection ....................................................... www.cancerconnection.org
Cancer Hope Network ................................................... www.cancerhopefoundation.org
Cancer Information and Counseling Line ..................... 800-525-3777
Cancer Really Sucks! ...................................................... www.cancerreallysucks.org
Cancer Support Community .......................................... www.cancersupportcommunity.org
Cancer Support Helpline .............................................. 888-793-9355
Cancer Survivors Network ............................................. http://cson.cancer.org
Cancer Wellness Center ............................................... www.cancerwellness.org
Caregiver Action Network ............................................. www.caregiveraction.org
CaringBridge .............................................................. www.caringbridge.org
Center to Advance Palliative Care ................................... www.capc.org
The Children’s Treehouse Foundation ............................ www.childrensreeeusefoundation.org
Cleaning for a Reason .................................................... www.cleaningforareason.org
Cooking with Cancer .................................................... www.cookingwithcancer.org
Cuddle My Kids .......................................................... www.cuddlemykids.org
Family Caregiver Alliance ............................................ www.caregiver.org
Fighting Chance .......................................................... www.fightingchance.org
Friend for Life Cancer Support Network ......................... www.friend4life.org
The Gathering Place ..................................................... www.touchedbycancer.org
Guide Posts of Strength, Inc. ........................................... www.cancergis.org
The Hope Light Foundation ............................................. www.hopelightproject.com
Imenman Angels ......................................................... www.imenmanangels.org
The LGBT Cancer Project – Out With Cancer ................. www.lgbtcancer.org
LIVESTRONG Foundation ............................................. www.livestrong.org
LivingWell Cancer Resource Center ............................. www.livingwellinc.org
Lutsa Helping Hands ..................................................... www.lutsahelpinghands.com
MyLifeLine.org Cancer Foundation ................................. www.mylife line.org
Patient Empowerment Network ..................................... www.powerfulpatients.org
Patient Power ............................................................ www.patientpower.info
PearlPoint Cancer Support ............................................. https://my.pearlpoint.org
SHARE Caregiver Circle .............................................. www.sharecancersupport.org/caregivers-support
Strike Out Cancer ........................................................ www.strikeoutcancer.com
Stronghold Ministry ..................................................... www.stronghold.org
Support Groups .......................................................... www.supportgroups.com
Triage Cancer ............................................................. www.triagecancer.com
Turning Point .............................................................. www.turningpointtc.org
Vital Options International ............................................. www.vitaloptions.org
Walk With Sally .......................................................... www.walkwithsally.org
Well Spouse Association .............................................. www.wellsouse.org
weSPARK Cancer Support Center .................................. www.wespark.org
Wonders & Worries ...................................................... www.wondersandworries.org

Complementary Programs & Alternative Medicine
Believe Big ............................................................... www.believebig.org
The Center for Mind-Body Medicine ............................... www.cmmb.org
Kansas City Healing Project .......................................... www.kansascityhealingproject.org
National Center for Complementary and Integrative Health ............................................................. www.nccih.nih.gov
Society for Oncology Massage ........................................ www.s4om.org
Stewarts Caring Place, Cancer Wellness Center ................ www.stewarts.caringplace.org
Touch, Caring and Cancer ............................................. www.partnersinhealing.net

Financial Assistance
BenefitsCheckUp ............................................................ www.benefitscheckup.org
Bringing Hope Home .................................................... www.bringinghopehome.org
CancerCare .............................................................. www.cancercare.org
Financial Cancer Financial Assistance Coalition ............ www.cancerfinancialassistance.org
The CHAIN Fund, Inc. .................................................... www.thechainfund.com
HealthWell Foundation ................................................ www.healthwellfoundation.org
Hope Lodge ............................................................... www.cancer.org/treatment/supportprograms/services/hopelodge
Medicare.gov ............................................................. www.medicare.gov
NeedyMeds ............................................................... www.needymeds.com
Partnership for Prescription Assistance ......................... www.ppdx.org
Patient Access Network Foundation ............................. www.panfoundation.org
Patient Advocate Foundation ......................................... www.patientadvocate.org
Patient Services, Inc. ..................................................... www.patientservicesinc.org
RxAssist ................................................................. www.rxassist.org
ReHopelink ............................................................... www.rehopelink.com
Social Security Administration ...................................... www.ssa.gov
Social Security Disability Resource Center ..................... www.ssrc.com
State Health Insurance Assistance Programs ................ www.shiptacenter.org
Stupid Cancer ............................................................ www.stupidcancer.org

Mental Health Services
American Psychosocial Oncology Society Helpline ............ 888-276-7443

Nutrition
American Cancer Society ............................................. www.cancer.org
CancerCare .............................................................. www.cancercare.org
LIVESTRONG Foundation ............................................. www.livestrong.org
OncoLink ..................................................................... www.oncolink.org
Patient Advocate Foundation ......................................... www.patientadvocate.org
Patient Services, Inc. ..................................................... www.patientservicesinc.org
RxAssist ................................................................. www.rxassist.org
ReHopelink ............................................................... www.rehopelink.com
Social Security Administration ...................................... www.ssa.gov
Social Security Disability Resource Center ..................... www.ssrc.com
State Health Insurance Assistance Programs ................ www.shiptacenter.org
Stupid Cancer ............................................................ www.stupidcancer.org

Pain Management
American Chronic Pain Association ................................. www.theacpa.org
Cancer Pain Research Consortium ................................ www.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 ..................................................... www.uspainfoundation.org

ADDITIONAL RESOURCES

GRACE provides cutting-edge information on optimal cancer management directly to patients through a variety of interactive channels: http://cancergrace.org/about-us

→ Sign up to receive GRACE Notes, our free member newsletter: http://grace.expert/Newsletter
→ Be part of our discussion forums: http://cancergrace.org/discussion-forums
→ Follow us on Facebook: https://www.facebook.com/cancerGRACE
→ Follow us on Twitter: https://twitter.com/CancerGRACE