

ASCO[®]answers

Cancer Survivorship



**Practical and Trusted Information to Manage Life After
Cancer from the American Society of Clinical Oncology**

Cancer.Net[®]

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ASCO furthers its mission through Cancer.Net and Conquer Cancer, the ASCO Foundation.

Cancer.Net (www.cancer.net), brings the expertise and resources of ASCO to people living with cancer and those who care for and about them. All the information and content on Cancer.Net is developed and approved by members of ASCO, making Cancer.Net an up-to-date and trusted resource for cancer information.

Conquer Cancer, the ASCO Foundation (www.conquer.org), funds research for every cancer, every patient, everywhere. As ASCO's foundation, Conquer Cancer supports groundbreaking research and education so both doctors and patients have the resources they need.

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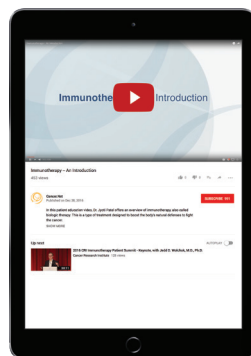
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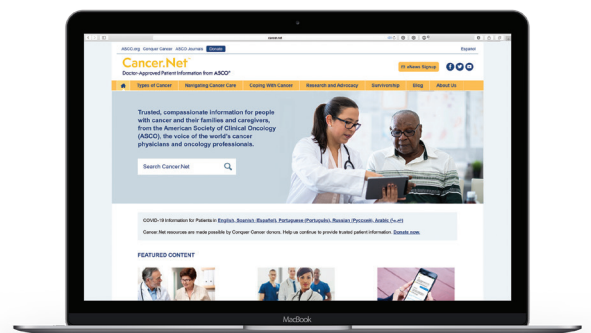
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Table of Contents

1	TABLE OF CONTENTS
2	INTRODUCTION
3	WHAT IS SURVIVORSHIP?
3	Defining survivorship
4	FOLLOW-UP CARE
4	Watching for recurrence
6	Managing late and long-term side effects
10	Keeping a personal health record
11	LIFE AFTER TREATMENT: WHAT TO EXPECT
11	Fear of recurrence
14	A new perspective on your health
17	Personal reflection
18	Changes within families and relationships
22	Starting or expanding your family
24	Going back to work
28	Managing your finances
30	SUPPORT FOR COPING WITH CHALLENGES
30	Cancer rehabilitation
36	Survivorship support groups
37	Other support resources
38	MAKING A DIFFERENCE
40	SURVIVORSHIP DICTIONARY
43	WORKSHEETS

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Introduction

As you finish cancer treatment, you might be wondering: What happens next? The answer is different for every person. Some people return to the lives they were leading before their diagnosis, while the lives of others are significantly changed by their cancer experience. The challenge for every survivor is figuring out how to return to everyday life while adjusting to the effects of the disease and its treatment.

Recognizing these challenges and knowing how and when to ask for support can help you through this time of transition. Using this *ASCO Answers* guide may also be helpful. This booklet was designed to help survivors and their families and friends prepare for life after cancer treatment. Throughout this guide, you will find questions to ask your doctor, nurse, or another health care professional, as well as plenty of space to write down their answers or other important information. There are also workbook pages you can complete with the help of a member of your health care team to keep track of important information about your diagnosis, cancer treatment, and follow-up care.

However you choose to accurately keep track of this information, it is important for your future health to do so. Don't be afraid to ask questions or to let your health care team know if you don't know what questions to ask.



What Is Survivorship?

Thanks to advances in medical research, the effectiveness of cancer treatment continues to improve. As a result, the number of people with a history of cancer in the United States has increased dramatically, from 3 million in 1971 to about 17 million today. As more people are surviving cancer, it is important to focus on living well after treatment.

Survivorship means different things to different people, but it often describes the process of living with, through, and beyond cancer.

Defining survivorship

The word “survivorship” is often used in several different ways. One common definition is having no signs of cancer after finishing treatment. Another common definition is living with, through, and beyond cancer. According to this definition, cancer survivorship begins at diagnosis and continues during treatment and through the rest of a person’s life.

No matter how it is defined, survivorship is different for everyone. In addition, some people dislike the word “survivor” and don’t identify with it. Everyone has to find their own path to name and navigate the changes and challenges that arise as a result of their cancer diagnosis and treatment.

My definition of survivorship:



QUESTIONS TO ASK ABOUT SURVIVORSHIP

- ▶ Will I need to have any additional treatment after active treatment has finished?
- ▶ Who will be part of my health care team after active treatment ends, and what will each member do?
- ▶ Are there groups or online resources you would recommend to help me learn more about survivorship for my specific diagnosis?
- ▶ If I have questions or problems, who should I call?

Follow-Up Care

Cancer care does not always end when active treatment finishes. After cancer treatment is completed, your doctor may continue to monitor your recovery, manage any lingering side effects, and check to make sure the cancer has not returned. Your follow-up care plan may include regular physical examinations and/or medical tests during the coming months and years.

Talk with your health care team about any concerns you have about your future health. They can give you information and tools to help you immediately after cancer treatment has ended and for the long term. You will likely continue to see both your primary care physician and oncologist after treatment has ended. This can make it difficult to figure out who will answer questions you have about your health and ongoing care. To prepare yourself, have a discussion with your health care providers about how your care will be coordinated and who will lead and plan your ongoing medical care. This decision depends on several factors, including the type and stage of the cancer, treatment side effects, health insurance rules, community resources, and your personal preferences.

Participating in follow-up care and keeping a medical support system in place are essential for maintaining both your physical and emotional health. It also helps many survivors feel in control as they transition back into their everyday lives. If you have any concerns about following the recommended follow-up care plan, talk with your health care team.

■ Watching for recurrence

One goal of follow-up care is to check for a recurrence of cancer. A recurrence is when the cancer comes back after treatment. Cancer may recur because some cancer cells remain in the body. Over time, these cells may increase in number until they show up on test results or cause signs or symptoms. Depending on the type of cancer, this can happen weeks, months, or even many years after the original cancer was treated.

A recurrence may be local, which means the cancer has come back in the same part of the body where the original cancer was located; regional, which means it has returned in an area near the original location; or distant, which means it has returned in another part of the body. It is important to know that if a cancer recurs far from the location of the original cancer, it is still named for the part of the body where the original cancer began. For example, if someone treated for breast cancer now has cancer in the liver, doctors will say they have metastatic breast cancer (breast cancer that has spread to another part of the body), not liver cancer.

The chance that a cancer will recur and the most likely timing and location of a recurrence depend on the type of cancer you were originally diagnosed with. Unfortunately, it is impossible for doctors to know who will experience a recurrence. Still, a member of your health care team familiar with your medical history can give you more personalized information about your risk of recurrence and possibly suggest ways to reduce this risk.



To help find signs of a potential recurrence, your doctor or another member of your health care team will ask specific questions about your health and usually do a physical examination during your follow-up visits. Some people may also have blood tests or imaging tests. Your follow-up care will be based on the treatment and care recommendations for your specific diagnosis. These recommendations for follow-up care are based on scientific evidence from research as well as what experts in the field agree provides the best results for people who have had that type of cancer. In addition, your doctor may tell you to watch for specific signs or symptoms of recurrence.

If a recurrence is suspected, your doctor may order additional diagnostic tests, such as blood and/or urine tests, imaging tests, or biopsies, to learn as much as possible about the recurrence. After testing is done, you and your doctor will review the results and then talk about treatment options.

Signs or symptoms I should report right away:



QUESTIONS TO ASK ABOUT CANCER RECURRENCE

- ▶ How likely is it that the cancer will return?
- ▶ What symptoms may be signs of a potential recurrence? Which should I report to you right away? Which should I report at my regular follow-up visits?
- ▶ What can I do to lower my risk of the cancer coming back after treatment?

Managing late and long-term side effects

Most people expect to experience side effects during treatment. However, it is often surprising to survivors that some side effects may linger after treatment, called long-term side effects, or that other side effects may develop months or even years later, called late effects. Other health conditions you may have, such as diabetes or heart disease, may also be made worse by cancer treatment. These long-term effects are specific to certain types of treatment and usually develop within a defined time.

Your doctor will be able to tell you if you are at risk for developing any late effects based on the type of cancer you had, your individual treatment plan, and your overall health. Some of the potential long-term side effects of cancer treatment are described here.



Attention, memory, and thinking problems. People who have been treated for cancer may have problems thinking and concentrating, paying attention, remembering things, and using language. This can be called many names, including cancer-related cognitive impairment, chemobrain, and chemofog, regardless of the type of treatment they received. These problems can be common in people who have had cancer, especially those who have cancer-related fatigue. The effects vary in severity and sometimes make it hard to complete daily activities. People who experience severe problems concentrating, multitasking, or understanding or remembering things should talk with a member of the health care team to learn about ways to manage these issues.

Bone, joint, and soft tissue problems. Cancer survivors who received chemotherapy, steroid medications, or hormonal therapy may develop thin or weak bones, called osteoporosis, or experience joint pain. You can lower your risk of osteoporosis by avoiding tobacco products, eating foods rich in calcium and vitamin D, and doing some types of regular physical activity, such as walking or biking. Your doctor may also prescribe medications that slow the rate of bone thinning, reduce new bone damage, and may promote bone healing.

Digestion and swallowing problems.

Chemotherapy, radiation therapy, and surgery may affect a person's ability to swallow or how well a person digests food. Certain types of cancer may also cause these problems. Additionally, some survivors may have chronic diarrhea that reduces the body's ability to absorb nutrients. If you have poor digestion, a dietitian can provide personalized nutrition advice and eating plans. These might help you get enough nutrients and may help you return to a healthy weight. If you are having trouble swallowing, talk to your health care team to receive support. You may need to learn new ways of swallowing, tips for making swallowing easier, or further treatment.



Emotional difficulties. Cancer survivors often experience a range of positive and negative emotions, including relief, a sense of gratitude to be alive, fear of recurrence, anger, guilt, depression, anxiety, and isolation. Survivors, caregivers, family, and friends may also experience post-traumatic stress disorder, which is an anxiety disorder that may develop after experiencing an extremely frightening or life-threatening situation. Talk with a nurse, social worker, or another member of your health care team if you are finding it difficult to cope with your emotions or if they begin to negatively affect your daily activities or relationships.

Fatigue. Fatigue is a persistent feeling of physical, emotional, or mental tiredness or exhaustion. Cancer-related fatigue is different from the fatigue that a healthy person may experience because it is not relieved by sleep and rest. It is the most common side effect of cancer treatment, and some cancer survivors experience fatigue for months and sometimes years after finishing treatment. Fatigue can seriously affect all aspects of a person's life, from relationships with friends and family to the ability to perform at work. It is important to tell your doctor if you are experiencing fatigue because there may be things your health care team can do to help.

Heart problems. Heart problems are most often caused by radiation therapy to the chest and specific types of chemotherapy and targeted therapy. Heart problems that are linked to cancer include damage to the heart, swelling of the heart, blockage or scarring of the blood vessels of the heart, irregular heartbeat, damage to the heart valves, and problems with the pericardium, which is the outer membrane of the heart. Talk with your health care team to find out if you should have regular heart evaluations.

Hormone (endocrine system) problems. Some types of cancer treatment may affect the endocrine system, which includes the glands and other organs that are responsible for making hormones and producing eggs or sperm. For example, people who receive radiation therapy to the head and neck area may have lower levels of hormones or changes to the thyroid gland.

Surgical removal of the ovaries, chemotherapy, hormonal therapy, and radiation therapy to the pelvic area may cause lighter and fewer regular menstrual periods or stop menstruation completely. Menstrual periods may return for some younger survivors after treatment, but those older than 40 are less likely to have their menstrual periods return. In some cases, cancer treatment may cause menopause. Talk with your health care team about how cancer treatment may affect your ability to have children. People with prostate cancer who receive hormonal therapy or who have their testicles removed may experience symptoms similar to menopause, such as hot flashes and weight gain.

Lung problems. Chemotherapy and radiation therapy to the chest may also damage the lungs, causing changes in how well the lungs work, thickening of the lining of the lungs, inflammation, and difficulty breathing. Cancer survivors who received both chemotherapy and radiation therapy to the lungs may have a higher risk of lung damage. Talk with your health care team about your risk for lung problems and how this will be monitored.

Lymphedema. Lymphedema is the abnormal buildup of fluid in soft tissue caused by a blockage in the lymphatic system. It occurs in areas where lymph nodes have been damaged. Often lymphedema affects an arm or a leg. For example, people treated for breast cancer may develop lymphedema in an arm. People treated for genitourinary cancers, like bladder or kidney cancer, may develop lymphedema in a leg. Lymphedema may also occur in other parts of the body, including the breast, below the chin, in the face, and, less often, inside the mouth. In some cases, the swelling goes away on its own as the body heals and normal lymph fluid flow resumes. Lymphedema may become chronic when the lymphatic system can no longer meet the body's demands for fluid drainage. There is no cure for chronic lymphedema; however, there are ways to manage it.

Peripheral neuropathy. Peripheral neuropathy is a type of nerve damage that develops when the nerves that carry information back and forth between the brain and spinal cord are damaged. This damage can be caused by radiation therapy, some types of chemotherapy, or by the cancer itself. Depending on which nerves are affected, a person can develop numbness, tingling, pain, or muscle weakness, usually in the hands and feet. If you develop symptoms of neuropathy, talk with your health care team. They can work with you to create a plan to treat your symptoms.

Secondary or subsequent cancers. Sometimes a person may develop a different type of cancer as a late effect of treatment. This may be caused by any of a number of factors, including previous cancer treatment, such as chemotherapy or radiation therapy, an inherited risk passed through the family, environmental exposures, and other risk factors, such as tobacco use, alcohol use, and obesity. Learn more about ways to reduce your risk of subsequent cancers on page 14.

Other physical effects. Cancer treatment can change a person's body. For example, survivors of cancers of the bone and soft tissue may experience physical and psychological effects from losing all or part of a limb, such as phantom limb pain, which is a feeling of pain that appears to be in the limb that was removed. To help survivors cope with these side effects and maximize their physical abilities, there are rehabilitation services available (see page 30).

If you had a treatment known to cause specific late effects, your doctor may recommend scheduling regular physical examinations, scans, or blood tests to help identify and manage them. Talk with your health care team about which tests are recommended based on your treatment plan and how often you should have them. Some side effects can be managed by specialists with specific expertise, such as speech pathologists and physiatrists. It may be helpful to ask for a referral to a specialist for your specific late or long-term side effects. You can write down this information on page 44.



For more information about the possible long-term effects of cancer treatment, visit www.cancer.net/lateeffects.

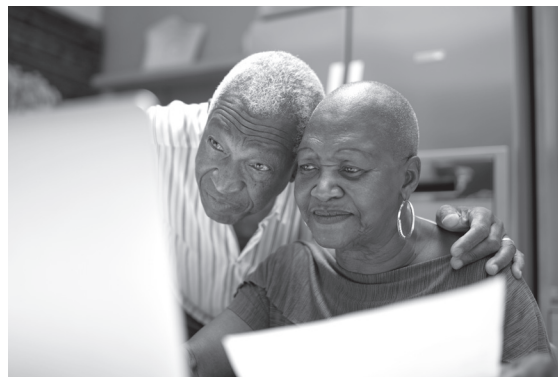


QUESTIONS TO ASK ABOUT LATE AND LONG-TERM SIDE EFFECTS

- ▶ What can be done to manage any long-term side effects, which are side effects that continue after treatment?
- ▶ What are the most common long-term effects that may develop based on my treatment plan?
- ▶ What are the most common late effects that may affect me? Late effects arise months or years after cancer treatment has ended.
- ▶ What screening tests do you recommend based on my cancer history?
- ▶ Are there other doctors or specialists I should see, such as a cardiologist or endocrinologist?

Keeping a personal health record

As time passes, it can be difficult to remember every detail of your diagnosis and treatment plan. At the same time, this information is very valuable to the doctors and clinicians who will care for you throughout your lifetime. To keep track of the most important information about their diagnosis and treatment, many survivors fill out a cancer treatment summary with the help of a member of their health care team and keep it with their health records.



Many survivors also ask their health care team for a survivorship care plan or follow-up care plan. This serves as a guide for monitoring and taking care of survivors' health in the future. This plan is usually based on medical guidelines for a specific diagnosis, as well as a person's individual needs and preferences.

On pages 43 and 44 you will find everything you need to start creating a cancer treatment summary and survivorship care plan with the help of the staff at your doctor's office. Keep this information in your personal health record, and share it with your current and future health care providers. Now is also a good time to review your other medical documentation, such as your advance directive, to make sure that it reflects your current and long-term wishes. To learn more about putting your health care wishes into writing, visit www.cancer.net/advancedirectives.



For cancer specific treatment summary forms and follow-up care plans, visit www.cancer.net/treatmentsummary.



QUESTIONS TO ASK ABOUT YOUR FOLLOW-UP CARE PLAN

- ▶ Who will be leading my medical care after I finish treatment?
- ▶ How do you usually provide survivorship care?
- ▶ Are there any survivorship clinics or other survivorship resources you would recommend?
- ▶ How often should I return for a follow-up visit with you? With my primary care physician?
- ▶ What tests will I need during my follow-up visits?
- ▶ Can you provide me with a summary of my cancer treatment?

Life After Treatment: What to Expect

In some ways, moving from active treatment to survivorship is one of the most complex aspects of the cancer experience because it is different for every person. After treatment ends, cancer survivors often describe feelings ranging from relief to fear. Some survivors say they appreciate life more and have gained a greater acceptance of themselves. At the same time, other survivors become worried about their health and uncertain of how to cope with life after treatment, especially when frequent visits to the doctor stop.

During treatment, people often feel actively involved in their care, and the relationships they develop with their health care team can provide a sense of support and security. After finishing treatment, the safety net of regular, frequent contact with the health care team ends. Survivors often miss this source of support, especially because new stresses and challenges may surface at this time, such as physical problems, emotional challenges, problems with sexual health, financial issues, and workplace discrimination.

The transition to survivorship is often complex and is different for every person.

■ Fear of recurrence

One of the most common concerns survivors have is worrying the cancer will come back. The fear of recurrence is very real and entirely normal. Thoughts like “Has the cancer come back?” and “What will happen if it does?” may be triggered by a physical sensation or symptom, such as a headache, cough, or joint stiffness, or it may come up before events like your diagnosis anniversary or follow-up appointments and tests. It is important to remember that although you cannot directly control whether the cancer returns, you can control how much the fear of recurrence affects your life.

■ Depression

For some survivors, life after cancer may also include depression. Depression often begins with feeling sad and losing interest in doing things that a person used to enjoy. This feeling is a common reaction after treatment, and normal sadness comes and goes. But if it is persistent and continues every day for more than 2 weeks, it may be what doctors call “clinical depression.” Depression can range from mild to

severe, and it can affect a person's ability to cope and make decisions about their care.

If you are depressed, talk with your health care team. There are treatments for depression that can help.

Ways to cope

Living with uncertainty is not easy, so it is important to develop a positive mindset and to focus on your ability to move forward with your life. Feelings of fear and anxiety will arise from time to time, but as time passes these emotions should not be a constant part of your life after cancer. Worrying about the cancer coming back is usually most intense the first year after treatment, but it generally gets better over time. Here are a few ideas to help you cope with the fear of recurrence.

Talk with your health care team. If you are concerned about your risk of recurrence, talk with your health care team. They can give you accurate information about the risk of recurrence for your type and stage of cancer and what to watch for. No one can predict exactly if a recurrence will or will not happen, but most cancers have a pattern of recurrence. Having this knowledge may help you cope with fear and distress.

Recognize your emotions. Many people try to hide or ignore “negative” feelings like fear and distress. However, ignoring them may allow them to intensify and become overwhelming. It often helps to talk about your fears and feelings with a trusted friend, family member, or mental health professional. Or you can try writing down your thoughts privately in a journal. Talking and thinking about your concerns can help you explore the issues that underlie your fear. This might include the fear of having to repeat cancer treatment, losing control over your life, or facing death.

Take care of yourself. Healthy habits like eating nutritious meals, exercising regularly, and getting enough sleep help people feel better both physically and emotionally. Avoid unhealthy or dangerous habits. Don't smoke, or quit smoking if you currently use tobacco. Limit the amount of alcohol you drink.

Do not worry alone. Many cancer survivors find joining a support group to be helpful. Support groups offer the chance to share feelings and fears with others who understand. They also allow you to exchange practical information and helpful suggestions. The group experience often creates a sense of belonging that helps survivors feel less alone and more understood. Other sources of social support may include your friends, organizations in your community, and faith groups.



Reduce stress. Finding ways to manage your stress will help you cope. Try different ways of reducing stress to find out what works best for you. This could include spending time with family and friends, rediscovering old hobbies, doing new activities you enjoy, taking a walk, meditating, enjoying a bath, exercising, or laughing at a funny book or movie. For more suggestions, see “Managing stress” on page 16.

If you find that you are consistently distressed or need additional help coping with uncertainty, talk with your health care team and consider a referral for counseling.



QUESTIONS TO ASK ABOUT COPING WITH FEAR AND DISTRESS

- ▶ What can I do to support my emotional health during my transition into survivorship?
- ▶ What are some healthy ways for me to deal with my feelings?
- ▶ What support services are available to me? To my family?
- ▶ What are some things I can do to manage my fears?

A new perspective on your health

For many people, the transition to survivorship serves as strong motivation to make lifestyle changes. Although cultivating healthy habits is a good idea for anyone, it is especially important for cancer survivors. This is because, as mentioned previously, survivors are often at higher risk for developing other health problems as a result of their cancer treatment. Healthy behaviors can help survivors regain or build strength, reduce the severity of side effects, reduce the risk of developing secondary or subsequent cancers or other health issues, and enjoy life more.

If you decide to make changes to your lifestyle, it is important to set realistic goals and to recognize that change does not happen overnight. By setting your mind on accomplishing small, achievable goals each day, you will be working toward the larger lifestyle changes you want to achieve. Talk with your health care team about specific lifestyle changes you might want to pursue. These could include:

Stopping tobacco use

Stopping tobacco use is the single most important change a person can make to lower future cancer risk. Tobacco is linked to an increased risk of at least 15 types of cancer. If you smoke or use tobacco of any kind, making an effort to quit can also improve your recovery and overall health. Exposure to secondhand smoke is also dangerous, so other members of the household should be encouraged to quit smoking, too.

Recommendations or referral:



Many resources are available to help, including quit lines, support groups, medications, and counseling, and can be found at www.cancer.net/tobacco.

Reducing alcohol intake

In addition to tobacco, alcohol is another substance consistently linked to cancer. Talk with your health care team about what amount of alcohol consumption is safe for you. In general, experts recommend that women have no more than one alcoholic drink per day and men consume no more than two. One drink is defined as 12 ounces (oz) of beer, 5 oz of wine, or 1.5 oz of 80-proof liquor.

Recommendations or referral:

❑ Eating well

Choosing to eat nutritious, healthy meals may help cancer survivors regain strength after treatment. Focus on building an eating plan high in vegetables, fruits, and whole grains. Eat in moderation to maintain a healthy body weight. Talk with your health care team about which resources are available to help you eat well. A registered dietitian can help you understand your nutritional needs, make healthy eating choices, and create tasty and appropriate meal plans.

Recommendations or referral:

❑ Exercising regularly

The American College of Sports Medicine recommends that survivors exercise regularly. Start slow and build up. Aim to do at least 150 minutes of moderate aerobic exercise, like walking, every week and resistance (strength) training two or three days per week.



Research is starting to link exercise with improved quality of life for cancer survivors. Regular physical activity can help survivors reduce anxiety, depression, and fatigue; improve self-esteem; increase feelings of optimism; improve heart health; reach and maintain a healthy weight; and boost muscle strength and endurance. Exercise also reduces the risk of high blood pressure, heart disease, stroke, and diabetes. In addition, some studies have shown that exercising regularly may help prevent the recurrence of breast, colon, prostate, and ovarian cancers.

Remember, even a small amount of physical activity is helpful. Talk with your health care team before you start an exercise program because you may need to adapt the types of exercises you do to your specific needs and limitations. A certified health and fitness professional can help you develop a plan based on your specific recommendations, but this is not typically covered by insurance.

Recommendations or referral:



Managing stress

Being diagnosed with a serious illness like cancer is very stressful, and everyday life often adds to this stress. Learning how to manage stress is extremely important for your recovery. Experiencing high levels of stress for a long time has been linked to health problems and a lower quality of life. A big step in reducing stress can be made through small changes in your life, such as learning to say “no” to tasks you don’t have the time or energy to complete, doing your most important tasks first, and getting help with potentially challenging issues such as finances.

Other ways to manage stress include exercise, social activities, support groups, mindfulness, acupuncture, yoga, tai chi, massage, and other relaxation techniques. Many relaxation techniques can be learned in a few sessions with a counselor or in a class.

Recommendations or referral:

Other:

Personal reflection

Many survivors struggle with questions of why they had cancer and why they survived when others have not. Some survivors may find themselves re-examining long-held views or beliefs as they try to make sense of their experience and find new meaning in life. Although every person creates meaning from their experiences in their own way, other cancer survivors have said they have found answers to some of these difficult questions by:

Re-evaluating old patterns and priorities. Some survivors look at their cancer experience as a “wake up call” and begin to ask questions like: Are my current roles in my family or as a friend fulfilling? Does my job make me happy or am I just doing what other people expect me to do? What are the most important things in my life now?

Reaching out for spiritual support. For some, spirituality and faith are a source of comfort and guidance. Many hospitals and cancer centers have chaplains who can give support to people of all faiths, as well as those who don't consider themselves religious at all. Local cancer organizations may also be able to help you find religious or spiritual leaders in your community who have experience helping cancer survivors.

Keeping a journal or blogging. Writing down your thoughts and feelings starts a process of self-discovery and, for some, of spiritual development. Allowing yourself to think every day or every week about your feelings is a way to get to know yourself better and to understand what is important to you now. Because blogging is much more public than journaling, it may also connect you with, and help inspire, other people who are going through a similar situation. At the same time, be sure you carefully consider what you want to publicly share about yourself and your medical history in a blog or through social media.

Finding new ways to support emotional well-being. Some survivors choose to begin new activities, such as yoga, meditation, drawing, or music therapy, that help support their spiritual and emotional health and make them feel less fearful and distressed. Other people become more active on social media as a way to gather information and cope.



Changes within families and relationships

As any person with cancer knows, a cancer diagnosis also affects family members and friends. Sometimes, the complex feelings and lifestyle changes caused by cancer and its treatment may become overwhelming to those who care about you. Understanding how cancer can change the way you relate to specific family members and friends may help you take steps to grow healthy, mutually supportive relationships during life after cancer.



Spouses and partners

Cancer has a major effect on marriages and other long-term partnerships. After cancer, both individuals may have experienced sadness, anxiety, anger, or even hopelessness. The effects of cancer vary from couple to couple. For some couples, facing the challenges of cancer together strengthens their relationship. For others, the stress of cancer may create new problems and worsen existing problems.

Here are some changes that often occur in relationships:

Roles. Cancer often changes roles in the relationship. A person who has always been in charge or served as the caregiver may have trouble accepting a more dependent role. Or a person who has not served in those roles may struggle to take charge and provide care. Talk with your partner about your feelings and work together as much as possible to make decisions about life after cancer.

Responsibilities. In many relationships, each partner handles specific chores. One partner may do yard work and cook, while the other cleans and pays bills. Your partner may have had to take up extra duties because of cancer treatment.

These added responsibilities for your partner may become overwhelming and lead to feelings of frustration and resentment. The change in your responsibilities may leave you feeling guilty, saddened, or frustrated. Talking openly about your responsibilities as a team will help you both feel more comfortable as you move into life after treatment.

Physical needs. The physical needs that come with cancer change throughout the course of the disease. It is important that both partners talk about their needs. Asking for help may be difficult, but your partner may not know that you need help or may not want to offend you by offering it. So it is important to talk openly and to clearly express your needs. This will help avoid the frustration and anger that could result from misinterpreting your spouse's or partner's behavior.

Emotional needs. Each partner may have different emotional needs that change frequently. But both partners may need extra reassurance that they are still loved. Couples need to be sensitive to the changing emotional needs that come with a cancer diagnosis. Each partner may find it difficult to express certain feelings for fear of hurting or overwhelming their partner. Individuals may want to consider talking with a professional, such as a therapist or counselor, on their own.

Future plans. Cancer often changes a couple's hopes and dreams. Your plans for retirement, traveling, or parenthood may change, causing feelings of sadness or even anger. It helps to reevaluate your priorities and work together to establish new, short-term goals. Things that seemed important before the cancer diagnosis may give way to new priorities, such as enjoying more time together. But putting some goals on hold, rather than changing them completely, may help your outlook on the future.

Friends and adult family members

The effects of cancer on your relationships with friends and family members may vary widely. Different families have different communication and coping styles.

Here are some suggestions to help you adjust to relationship changes with friends and family:

Expect relationships to change. Many people have little experience with life-threatening illnesses. They may not know what to say to you or how to act. For some, it may be frightening to learn that you have cancer. Others may have lost a loved one to cancer, and your diagnosis may bring up painful memories. For these reasons, some of your friends or family members may not be able to offer you the support that you expect.

Although this is painful, try to remember that their reactions may reflect their past experiences and losses and not their feelings for you. Some friends and family members may distance themselves from you, but others will surprise you with emotional and physical support throughout your illness.

Take the lead in talking. Some friends and family members may avoid talking with you because they do not know what to say. Others may avoid talking about cancer, fearing that they will upset you. If you feel like talking about your cancer, bring up the subject with your friends and family members. Let them know that it is okay to talk about it. Reassure them that you do not expect answers and that you only want them to listen and to try to understand your feelings. It is also okay to tell people when you do not want to talk about cancer. At times, you might prefer to talk about other things or just laugh with your friends.

Children

There are specific challenges for parents who have finished cancer treatment.

Communication. You may want to protect your children from difficult feelings associated with cancer. But it is important to talk openly with them about what you have experienced and what the future holds. Open communication will help your children cope, but provide information that is appropriate for your children's ages. This will help them understand the situation without overwhelming them.



A social worker or counselor can help you have these conversations.

Changes in children's behavior. Your children's behavior may have changed in response to your cancer treatment. Those behaviors may need your attention to help them cope with their emotions. Start by talking with your children. Encourage children to ask questions, and let them know it is okay to talk about their feelings and fears. Reassure your children that they will always receive care and that you will always love them.



Read more about talking about cancer with children at www.cancer.net/talkingwithchildren and www.cancer.net/howchildrenunderstand.

Role reversal. Adult children may have had to become caregivers for a parent with cancer. This is a change that is often difficult for both parents and children.

Balancing your needs and your children's needs. Although cancer treatment has ended, you may not be able to return to parenting as before your diagnosis. This is the time to reconsider your schedule, to-do list, goals, and expectations as a parent. Accept help from others and ask for help when you need it. This will allow you to spend less time worrying and more time enjoying your loved ones.

Sexual health and intimacy

In general, although people are less interested in sex while having cancer treatment and at times of crisis, interest in sex usually improves during recovery and survivorship. However, some survivors may experience changes in their sexual function or sex drive caused by cancer and cancer treatment.

Some treatments, even those not directed at the pelvic area or groin, can cause physical side effects that interfere with sexual function. But even other physical changes not directly related to sexual function may affect the way a person feels about their body and their physical attractiveness, such as losing a testicle or a breast, needing a colostomy or another type of ostomy, losing weight or hair, or having scars or skin changes. Even a person whose body was not outwardly changed by cancer may feel differently about their body. All of these changes affect self-image, self-confidence, and a person's sense of attractiveness.

Even though it may feel awkward or uncomfortable, it is important to discuss what you are experiencing with a member of your health care team. If a doctor or clinician does not seem comfortable or experienced with these concerns, there are professionals who can help. Ask for a referral to a psychologist, sex therapist, urologist or gynecologist, or other professional who treats sexual difficulties.

Intimacy is very closely connected to your feelings about your relationship as well as your feelings about yourself. Therefore, finding a counselor who has experience working with people with cancer and talking through some of these issues can help both you and your partner.

Good communication involves talking openly and honestly about your thoughts, feelings, and fears with someone who listens and supports you. Good communication includes not only sharing your own thoughts and feelings, but also listening to the other person's thoughts and feelings and accepting them without criticism or blame. By establishing open and ongoing communication with your spouse or partner, you both can better adapt to the changes cancer has caused in your lives as well as in your relationship.



QUESTIONS TO ASK ABOUT SEXUAL HEALTH AND INTIMACY

- ▶ How can sexual side effects be relieved or managed, if they do occur?
- ▶ Can sexual side effects occur after treatment ends?
- ▶ Is it safe for me to have sex during cancer treatment? Is it safe for my partner?
- ▶ Would you recommend that I talk with a counselor or sex therapist?

Starting or expanding your family

Deciding when and whether to have a baby is often a difficult decision for survivors. There are a number of emotional and physical factors that both survivors and their spouses/partners need to consider before starting or adding to their families.

In general, becoming pregnant after cancer treatment is considered safe for both the mother and the baby. However, the exact amount of time survivors should wait before trying to become pregnant depends on the type and stage of cancer, the type of treatment received, any need for ongoing treatment, and their age and personal preferences.



If you are considering having a baby, you also should talk with your health care team about whether your body can safely handle pregnancy. Sometimes, cancer treatments damage specific areas of the body, such as the heart or lungs. Before becoming pregnant, these organs may need to be checked to be sure pregnancy will be safe. You may be referred to an obstetrician who specializes in caring for patients during and shortly after a pregnancy when they have other health concerns.

If you are planning to father a child, there are no specific guidelines for trying to have a child after finishing cancer treatment. However, doctors may recommend waiting before trying to have a child, with the exact amount of time depending on a number of factors.

Dealing with infertility

Some couples find that cancer treatment has made it difficult or impossible for them to have children, leading to intense grief and anger. It is important to find support as you cope with these changes and losses. Your doctor, clinician, social worker, or counselor may also be able to help you look into other ways to start or expand your family.

Assisted reproduction. Cancer treatment and age may reduce the number of eggs in the ovaries, called the ovarian reserve, making it difficult for a pregnancy to happen. If blood tests and ultrasounds show this has occurred, a fertility specialist may be able to use assisted reproduction techniques, such as in vitro fertilization (IVF). During this process, a

survivor's eggs or donor eggs (see below) are fertilized with sperm outside the body. One or more of the fertilized eggs (embryos) are later put back into the uterus so they can develop into a baby. For the pregnancy to be successful, the uterus must be healthy, and the person will have to take hormones before and after the procedure.

Donor eggs. People with a low ovarian reserve may be able to use someone else's eggs to become pregnant. The donated eggs are fertilized in a laboratory with the sperm of a partner or of a donor using IVF techniques.

By law, all egg donors, whether they are a family member, friend, anonymous donor, or known donor from an agency, are screened for psychological issues, medical conditions, and potential genetic diseases before they are allowed to donate eggs.

Donor sperm. If someone who had cancer treatment did not store their sperm before starting treatment, they can use sperm donated to a sperm bank by someone else to become a father. In most cases, the sperm, which is screened for infectious diseases, is donated anonymously. However, sperm banks usually record the physical traits of the donor.

Testicular sperm extraction and epididymal sperm extraction. For people who do not have mature sperm in their semen, this procedure involves removing a small amount of tissue from the testicle. This tissue is examined under a microscope to find mature sperm, which can be frozen or used immediately for IVF.

Donor embryos. Donor embryos usually come from couples who had an infertility treatment that resulted in extra embryos. As with egg donation, the embryos are then transferred into the uterus of the person who wants a child, and they will have to take hormones before and after the embryos are inserted. Although a couple or individual who uses a donated embryo will not be genetically related to the child, the procedure allows someone with a healthy uterus to experience pregnancy. By law, the couple donating the embryos must have the same tests that are required for the egg donation process.

Surrogacy and gestational carriers. If someone is not able to carry a child, or if becoming pregnant could put their health at risk, having another person carry the baby during pregnancy is an option. This is called surrogacy if the person who will carry the child becomes pregnant through artificial insemination with the father's sperm. If an embryo created from the mother's egg and the father's sperm is implanted into someone else, that person is called a gestational carrier. Surrogacy and gestational carrier laws are different in each state, so it is important to consult an attorney if you are considering this option.

Adoption. Adoption is the permanent, legal transfer of parental rights of a child from the biological parent to another couple or individual. Although most adoption agencies allow cancer survivors to adopt, some require a letter from a doctor certifying good health,

and others may require a certain amount of time to pass after a person has completed treatment for cancer. If the adoption is taking place outside the United States, there may also be international rules related to the health of the adoptive parents.



For more information about having a child after cancer, visit www.cancer.net/survivorship/lifeaftercancer.



QUESTIONS TO ASK ABOUT HAVING CHILDREN

- ▶ Could cancer treatment affect my ability to become pregnant or have children?
- ▶ How long should I wait before trying to become pregnant or father a child?
- ▶ Will trying to have a child affect my follow-up care plan?
- ▶ Where can I find support for coping with fertility issues?
- ▶ Who should I contact if I need help talking with my spouse or partner about fertility issues?

Going back to work

For many people, returning to a full-time work schedule is a sign both to themselves and the world that they are getting back to “normal.” Working can provide opportunities to reconnect with colleagues and friends, focus on something other than cancer, get involved in interesting and challenging projects, and start settling back into a regular routine and lifestyle. However, transitioning back into the workforce may feel overwhelming at times.

Every survivor’s work situation is different. Many people with cancer who took time off for treatment return to work afterwards, while many others may have worked throughout treatment. Still others may not be able to return to work because of long-term side effects. Your decisions about work will likely depend on your financial resources, health insurance, the type of work you do, and the nature of your recovery.

Planning your return

For survivors who cut back on their hours or stopped working, the first step is to talk with their health care team about whether they can return to work. The timing depends on the type of cancer and treatment you had and the type of job you perform. If your job is stressful or physically demanding, you may need to wait longer before returning to work. Ongoing treatment or side effects, such as fatigue, may also cause delays.



Once you know you can return to work, a good next step is to set up a telephone or in-person meeting with your human resources department to discuss transition plans. Ask whether your employer has a formal “return-to-work” or disability management program. You may also want to discuss the possibility of flexible work arrangements, such as part-time hours, partial or full-time telecommuting, job sharing, reassignment to another position, leave time for doctor visits, or periodic work breaks to take medications and contact members of your health care team. These are all considered reasonable accommodations under the Americans with Disabilities Act (ADA).

Before granting a reasonable accommodation, your employer may request documentation that verifies your limitations, such as fatigue, chronic pain, and cognitive difficulties, which are classified as disabilities under the ADA. However, employers are not allowed to ask for your medical records. An employer may deny a request if the accommodation would cause an “undue hardship,” such as being too difficult or expensive to implement. However, an employer is required to determine if there is an easier or less costly accommodation that can be made to meet your needs.

Other things to consider to make your transition back to work smoother include:

- ▶ Planning to take small breaks throughout the day to help maintain your energy level
- ▶ Using lists and reminders or setting meeting and task alarms on your work e-mail system
- ▶ Scheduling frequent meetings with your manager to talk about the transition and make any necessary changes or adjustments

Talking with coworkers

It's your decision when and how to tell coworkers about your cancer experience, if you even decide to talk about it at all. However, if you have been absent for a while or your physical appearance has changed, some of your coworkers may have questions. It is important to decide what you want to tell people in advance and how you plan to do it. You may want to have private conversations with a few close coworkers. Or you may find it easier to send an e-mail or make an announcement at a staff meeting. Consider your work culture, what feels right to you, and your need for privacy versus your need for accommodations and support. You can also ask your manager, a close coworker, or a human resources professional to help you decide if, when, and how to tell others about your cancer.

It always helps to keep your explanation simple and let people know how your return to work will affect them. For example, you might consider saying: "I've completed treatment for cancer, and I'm currently doing well. It's good to be back at work. Just so you know, I will be here 20 hours per week for the next 4 weeks, and I will return full time after that. In the meantime, Joe Smith will be covering projects A and B."

Some employers and coworkers may not respond well. Their reactions usually have to do with past experiences or a lack of familiarity with cancer. However, most survivors find that their coworkers are supportive and caring. People often take your lead; if you are comfortable talking about your experience with cancer, they will likely feel the same.

Dealing with discrimination

Although many survivors can be as productive as they were before treatment, some find they are treated differently or unfairly. For example, some employers and colleagues may assume that a person's productivity will decrease or that performance will fall below the company's expectations. Other types of discrimination may include receiving a demotion for no clear reason, having an earned job promotion withheld, being overlooked for consideration in a new position, and finding a lack of flexibility in response to requests for time off for medical appointments.

It is important to understand that there are laws and regulations that prohibit discrimination, such as the ADA, and you can take legal action if necessary. However, it is often better to take steps to try to prevent discrimination when you return to work after cancer treatment by:

- ▶ Catching up on new projects or developments that occurred while you were gone
- ▶ Refreshing job skills, if necessary, by reviewing past work assignments or attending classes or workshops
- ▶ Seeking counseling from a professional about making the transition back to work
- ▶ Getting advice and tips from other cancer survivors through a support group
- ▶ Asking your doctor to write a letter stating your ability to return to work

Finding a new job

For some survivors, the cancer experience reshapes their career priorities and causes them to question whether they still want to continue on their current career path. Other survivors are unable to return to their previous job and must take their career in a new direction. No matter what the reason, the thought of applying and interviewing for a new job may make you uneasy.

When applying and interviewing for a new job, some cancer survivors worry about how they will explain gaps in their work history or their reasons for leaving positions they had before their cancer diagnosis or treatment. If you are concerned about explaining gaps in employment, it may be helpful to talk with a career counselor or social worker. They can teach you interviewing skills and help you organize your resume by experience and skills instead of by date.

During the interview process, an employer, by law, cannot ask questions about your health or about a medical condition, such as whether you have had cancer. If you choose to tell a potential employer about your cancer history, the employer is still not allowed, by law, to ask you any questions about the cancer, the treatment you received, or your recovery. The employer also must keep any information you share about your history of cancer or any other medical information confidential. An employer is allowed to ask questions related to the specific duties and responsibilities of the job, such as whether you can lift a certain number of pounds or travel.

Some job seekers find encouragement in support groups, which help them connect with other people who are looking for work. These groups also provide suggestions and tips on networking with potential employers and can be good resources for learning about potential job openings. In addition, books and career counselors can provide guidance on how to network effectively. Taking proactive steps can boost your self-esteem and help you stay positive while you are looking for employment.



QUESTIONS TO ASK ABOUT EMPLOYMENT CONCERNS

- ▶ If I am nervous or feel overwhelmed about returning to work, who can help me?
- ▶ If I have difficulty talking with my coworkers about my cancer experience, what are some coping strategies I can try?
- ▶ What information do I need to give my employer when I return to work? What information can remain private?
- ▶ If I have on-the-job difficulties when I return after treatment, who can help me understand my legal rights?



Managing your finances

The costs of cancer care can be high. Even people with reliable health insurance can be left with bills that quickly add up. Often, survivors have already lost income because they weren't able to work as much or at all during treatment, making it difficult to pay for both medical and household expenses. This financial stress may increase if you are unable to return to work after finishing treatment. Here are a few things to consider as you cope with the financial impact of cancer:

Investigate other sources of income if you are unable to return to work. If a disability or other long-term side effect of cancer treatment has made it impossible for you to return to work, there are a number of potential sources of income to consider, including long-term disability insurance, life insurance policies, and retirement plans. Some cancer survivors apply for Social Security Disability Insurance or Supplemental Security Income. To learn more about these federal programs, including eligibility requirements, call 800-772-1213 or visit www.ssa.gov/disability.

Organize bills and rank them in order of priority. As you open your bills, organize them into categories such as medical bills, household bills, credit card statements, taxes, etc. Then figure out how much money you have in your budget to put toward payments. Your rent or mortgage, utilities, taxes, and medical expenses should be at the top of your bill-paying list.

Make an appeal. If your insurance company has denied payment for a service or treatment, you have the right to ask them to conduct a full and fair review of its decision. If the company still denies payment after considering your appeal, the Affordable Care Act allows you to have an independent review organization decide whether to uphold or overturn the plan's decision.

Ask if the insurance payment can be considered “payment in full.” If you are unable to pay for tests, procedures, and other treatments that were not completely covered by your insurance plan, making this request to the hospital, cancer center, or doctor’s office is often more successful than people expect. Some hospitals have funds to offset medical services that aren’t fully covered by insurance.

Talk to your creditors. Usually if you call and explain your situation, your creditors or a credit counseling service will work with you to create a payment plan. Most companies would prefer receiving small payments, even \$10 a month, than nothing at all. Give the person you talk to a telephone number and the hours that you can be reached if there are any problems. Also ask them to communicate with you in writing.

Ask for help. If you can’t face the stack of bills that has collected, ask a trusted friend or family member to help you organize them and plan your budget. You can also talk with an oncology social worker or patient navigator about your financial concerns. They can help connect you with financial assistance programs and other sources of financial aid. Contact an organization that offers help for cancer survivors facing financial challenges. There are many national and local organizations that offer financial information, advice, and support for cancer survivors. Contact them directly to learn more about specific programs and services, including eligibility criteria.



For more suggestions and resources for managing the costs of cancer care, visit www.cancer.net/managingcostofcare.



QUESTIONS TO ASK ABOUT YOUR FINANCES

- ▶ How many more medical bills should I expect to receive related to my active treatment period?
- ▶ If my insurance claim is denied, who can help me file an appeal?
- ▶ If I am having difficulty paying my medical bills, are there organizations that can help?
- ▶ What resources and support are available to me if I am unable to return to work after finishing treatment?
- ▶ If I am having trouble paying for basic items, like food or heat, due to the cost of my cancer treatment, are there organizations that can help?
- ▶ Where can I get free or low-cost personal items after treatment, such as medical supplies, if needed?
- ▶ Who can help me understand what my insurance will cover in my recommended survivorship care plan, such as follow-up exams and medical tests?

Support for Coping With Challenges

Every cancer survivor has individual concerns and challenges, some of which may not have been addressed specifically in this guide. With any challenge, though, a good first step is being able to recognize your fears and talk about them. Effective coping requires understanding the challenge you are facing, thinking through solutions, asking for and allowing the support of others, and feeling comfortable with the course of action you choose.



Talking with your doctor, clinician, nurse, or another member of your health care team about any concerns you may have is an important part of your follow-up care, especially if something you are experiencing is holding you back from enjoying your life. Just as there were support options during treatment, there is also help for you during your transition into survivorship and beyond.

Effective coping requires understanding the challenge, thinking through solutions, and asking for support.

■ Cancer rehabilitation

Cancer and its treatment often cause physical, psychological, and cognitive problems. These problems can make it harder to do daily activities or return to work. They may also have a lasting effect on your health. Cancer rehabilitation can help with these problems, which can happen during and after cancer treatment. The goal of cancer rehabilitation is to:

- ▶ Help you stay as active as possible and participate in work, family, and other life roles
- ▶ Lessen the side effects and symptoms of the cancer and its treatment
- ▶ Help keep you as independent as possible
- ▶ Improve your quality of life

Cancer rehabilitation is given by trained rehabilitation professionals, such as:

- ▶ Physical therapists
- ▶ Occupational therapists
- ▶ Speech pathologists
- ▶ Psychiatrists
- ▶ Lymphedema therapists
- ▶ Cognitive psychologists
- ▶ Vocational counselors
- ▶ Recreational therapists
- ▶ Registered dietitians
- ▶ Exercise physiologists

Cancer rehabilitation services

Many cancer centers and hospitals offer a variety of cancer rehabilitation services to their patients and are able to help identify local resources. Survivors and family members are encouraged to be active, informed partners in the rehabilitation process and to talk with a nurse, social worker, or patient educator about the services they are interested in. These may include:

Certified health and fitness programs

These programs help survivors build strength, endurance, and mobility.

Recommendations or referral:

Clinical trials for survivors

These research studies may offer ways to improve a person's quality of life after cancer treatment.

Recommendations or referral:

Family counseling

When meeting with a family, a counselor listens objectively to all participants and helps identify how specific thoughts and behaviors could be contributing to conflict. Family members learn new ways to support each other during stressful times.

Recommendations or referral:

☐ Home care services

Home care consists of a range of professional health care and supportive services delivered in the home, including help with daily activities, such as eating, drinking, dressing, bathing, using the toilet, cooking, and basic housekeeping.

Recommendations or referral:

☐ Individual counseling

One-on-one interaction with a counselor gives people an opportunity to talk about troubling circumstances, thoughts, and feelings. The counselor will listen attentively, express caring concern, ask questions, and offer feedback.

Recommendations or referral:

☐ Marriage/couples therapy

The goal of this type of counseling is to help couples respond to challenges and associated emotions in healthy ways. It focuses on improving relationships and resolving conflict.

Recommendations or referral:

☐ Nutritional planning

A registered dietitian can provide guidance on a survivor’s specific nutritional needs, including meal planning, to regain and maintain a healthy weight and lifestyle.

Recommendations or referral:

Occupational therapy

Occupational therapy focuses on helping people with an illness, injury, or disability develop the skills they need to accomplish daily tasks, such as self-care and work, so they can regain or maintain their independence.

Recommendations or referral:

Oncology social worker consultation

Oncology social workers provide education, information services, discharge and home care planning services, and referrals to community resources. They also help survivors adjust to life after treatment by providing counseling on ways to cope with a variety of post-treatment issues, including practical, financial, and work-related challenges.

Recommendations or referral:

Pain management

Nearly all cancer-related pain can be successfully treated or managed. After a thorough medical assessment, your health care team will work with you to develop a pain management plan that may include medication, physical and occupational therapy, relaxation, distraction, hypnosis, biofeedback, nutritional support, and acupuncture. Some hospitals have pain specialists to help patients and survivors with pain that is difficult to control.

Recommendations or referral:



Learn more about pain at www.cancer.net/pain.

Physical therapy

A physical therapist will evaluate any nerve, muscle, or fitness problems that make it difficult for a person to function well on a daily basis and then develop a care plan. This plan usually includes exercises and other recommendations that improve a person’s physical functioning and help prevent further difficulties.

Recommendations or referral:

Recreational therapy

Recreational therapists work with survivors to reduce stress, anxiety, and depression through music, games, exercise, and arts and crafts.

Recommendations or referral:

Survivor matching programs

Also called buddy programs, these groups connect survivors with similar diagnoses, situations, or concerns to provide one-on-one peer support.

Recommendations or referral:

Tobacco cessation programs

These programs provide support and resources for quitting tobacco use. A variety of treatments and resources are available for people who want to stop using tobacco, including medications and counseling. Your chances of successfully quitting are better if you follow a comprehensive plan and build a support network.

Recommendations or referral:

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Learn more about stopping tobacco use by visiting www.cancer.net/tobacco.

❑ Vocational (career) counseling

Career counselors help survivors find or keep a satisfying job, especially if their cancer experience has reshaped their career priorities and caused them to question whether they fit with their current job. Career counselors can also provide guidance on how to network effectively, teach interviewing skills, and help organize resumes by experience and skills, instead of by date.

Recommendations or referral:



For more information about support resources and links to national organizations, online support communities, and age-specific resources, visit www.cancer.net/support and www.cancer.net/survivorship.



QUESTIONS TO ASK ABOUT CANCER REHABILITATION

- ▶ Would I benefit from cancer rehabilitation services? If so, what kinds of services?
- ▶ Who can help me understand what my insurance will cover for cancer rehabilitation services?
- ▶ What are other ways I can stay as healthy as possible after treatment?

Survivorship support groups

As you move from active treatment into survivorship, know that you are not alone. You have family, friends, and community resources there to help you manage the emotional, practical, and financial issues that arise as you transition back into “normal” life. Still, some survivors find it is helpful to talk with people who know what they are going through from first-hand experience.

Support groups offer the chance for people to talk about their experiences with other survivors. Group members can share feelings and experiences that seem too strange or too difficult to share with family and friends. The group experience, which is often led by a trained counselor, social worker, or psychologist, often creates a sense of belonging that helps each person feel less alone and more understood. Sharing feelings and fears with others who understand may also help reduce stress.

In addition to sharing feelings and experiences, support group members sometimes discuss practical information, such as what to expect after treatment, how to manage pain and other long-term side effects, how to deal with the fear of recurrence, and how to communicate with health care providers and family members. These informational support groups are usually led by a professional facilitator and focus on providing cancer-related information and education. These groups often invite speakers who can provide expert information.

Finding the right support group depends on your needs and personality. Some people may need emotional support, while others may prefer an emphasis on information and education. Some people join a group that is open to all individuals with cancer, while others may prefer a group that is more specialized, such as for those with a specific type of cancer (like breast cancer or prostate cancer) or a group that is dedicated to post-treatment survivors.

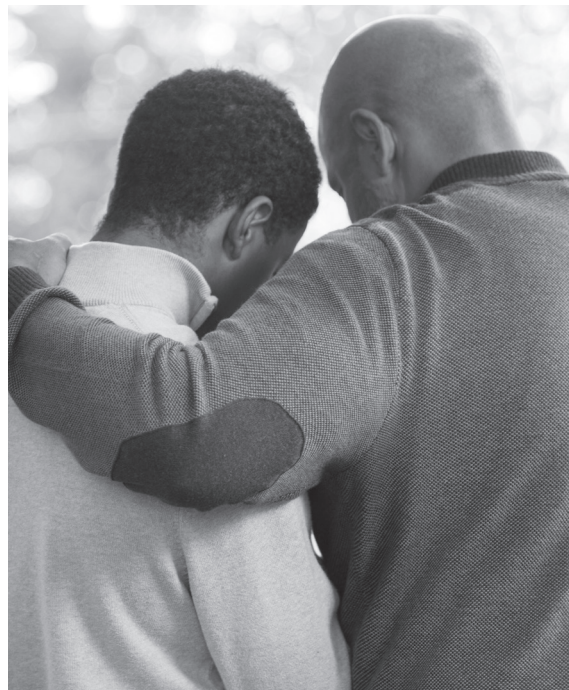
Online support groups are also an option. These groups may be helpful for people who live in rural areas or for those without easy access to transportation. An online support group may allow people with less common types of cancer to communicate with others with the same type of cancer. Online support groups may also be a good choice for those who do not feel comfortable sharing their experiences face-to-face.

Online communities or social networking sites can connect you with other survivors who share common interests or who are in a situation similar to yours. Many cancer advocacy organizations have online support groups as well.

Other support resources

Some people with cancer may not be interested in joining a support group or may find that support groups are not helpful for them. If this is true for you, there are other ways to find support that you may want to consider, such as:

- ▶ Talking with a friend
- ▶ Individual counseling or therapy
- ▶ Asking a doctor, clinician, or nurse specific questions
- ▶ Talking with someone who is a part of your spiritual or religious community
- ▶ Visiting the learning resource center at the hospital or cancer center where you received treatment
- ▶ Focusing on other enjoyable activities



Caregivers may also need time to adjust while the patient transitions to survivorship. Learn more by visiting www.cancer.net/aftercaregiving.



QUESTIONS TO ASK ABOUT FINDING SUPPORT

- ▶ What post-treatment support services are available to me? To my family?
- ▶ Where can I find resources for a child? For a teenager? For a young adult? For an older adult?
- ▶ Does this hospital or cancer center have a learning resource center? If so, where is it located?
- ▶ Can you recommend a social worker or other professional who can help me find additional survivorship support services?

Making a Difference

Positive feelings often arise during the transition to survivorship. Many survivors express a strong desire to “give something back” because of the care and kindness they received. Many realize they have a lot of valuable experience that can help others facing cancer. If you are interested in giving back, think about your own interests, strengths, and areas of expertise and how various organizations could use them to help further their mission.

There are a number of ways for survivors to make an important difference in someone else’s life and often make a positive difference in their own life at the same time. Many survivors say sharing their time makes them feel good, helps build new friendships, and widens their network of support. These opportunities include:

Volunteering makes an important difference in someone else’s life while making a positive difference in your own.

Service and support. Through these programs, survivors provide information and help people with cancer find ways to cope. Volunteer hotline counselors are trained to give easy-to-understand information over the phone and lend support by listening to patients’ concerns. Some support groups are organized and run by cancer survivors. There are also cancer support programs you can get involved in that offer emotional and practical support to patients and their families by providing needed items, such as wigs, scarves, and books.

Awareness and education. Through workshops and presentations at schools, workplaces, health fairs, and on the internet, cancer organizations raise awareness about this disease and educate people about cancer prevention and screening. Many also provide tips about maintaining a healthy lifestyle and follow-up care after treatment ends. Survivors can help by teaching sessions about cancer at their workplace, community center, or place of worship; providing office services and help with event planning and logistics for local cancer organizations; or joining committees that plan new educational programs.

Fundraising. Cancer organizations usually need to raise money to maintain services and programs, such as free cancer screenings, transportation assistance and financial aid for patients and their families, outreach programs, education, and research. Survivors often participate in fundraising activities, such as races and other sporting events, luncheons or dinners, plays or concerts, fashion shows, and auctions.



Advocacy. Being an advocate means supporting and speaking in favor of a specific cause. Survivors help lead local and even national efforts to develop or change cancer policy issues, such as access to health care and funding for cancer research. By working with cancer organizations, advocates can support legislation that helps people with cancer and their families and speak out about issues affecting people with cancer.

Survivors also advocate for cancer research by supporting clinical trials. Individual patient advocates can join a clinical trial cooperative group sponsored by the National Cancer Institute, review research grants, assist in the development of clinical trial protocols and informed consent forms, participate in community outreach and education regarding clinical research, help reduce barriers to participation in clinical research, and recruit patients to participate in specific clinical trials.



To learn more about advocacy and other ways to volunteer as a survivor, visit www.cancer.net/advocacy.



QUESTIONS TO ASK ABOUT VOLUNTEERING AND ADVOCACY

- ▶ How can I find cancer-related organizations to volunteer with?
- ▶ What are other ways I can support people living with cancer?
- ▶ How can I get involved in cancer research?

Survivorship Dictionary

Active treatment: The period when a person is having surgery, chemotherapy, radiation therapy, or other treatment to slow, stop, or eliminate the cancer.

Acute survivorship: A term describing the period when a person is diagnosed with cancer and/or receiving active treatment.

Americans with Disabilities Act (ADA): A federal (national) law that protects people with disabilities from discrimination. It requires employers to make reasonable accommodations in the workplace for qualified individuals with a disability. Learn more at www.ada.gov.

Anxiety: Feelings of nervousness, fear, apprehension, and worry.

Case manager: A health care professional who helps coordinate a person's medical care before, during, and after treatment. At a medical center, a case manager may provide a wide range of services, including managing treatment plans, coordinating health insurance approvals, and locating support services. Insurance companies also employ case managers.

Chemotherapy: The use of drugs to destroy cancer cells, usually by keeping the cancer cells from growing, dividing, and making more cells.

Clinical trial: A research study that involves volunteers. Many clinical trials test new approaches to treatment to find out whether they are safe, effective, and possibly better than the treatment doctors currently use. There are clinical trials about survivorship care, prevention, and other areas of cancer care.

Depression: Defined as having a low mood and/or feeling numb consistently for more than two weeks, every day and much of the day.

Extended survivorship: A term describing the period when a person has just completed active treatment, usually measured in months.

Fertility: Ability to become pregnant or have children or the ability to provide healthy sperm.

Follow-up care plan: A personalized schedule of follow-up examinations and tests that a doctor recommends after the active treatment period. This may include regular physical examinations and/or medical tests to monitor the person's recovery for the coming months and years. This may also be called a survivorship care plan; it is often used with a treatment summary.

Hormonal therapy: Treatment that removes or blocks hormones to destroy or slow the growth of cancer cells. Also called endocrine therapy.

Imaging test: A procedure or scan that creates pictures of internal body parts, tissues, or organs to make a diagnosis, plan treatment, check whether treatment is working, observe a disease over time, or check for a recurrence.

Laboratory test: A procedure that evaluates a sample of blood, urine, or other substance from the body to make a diagnosis, guide treatment, check whether treatment is working, observe a disease over time, or check for a recurrence.

Late effects: Side effects of cancer or its treatment that occur months or years after the active treatment period has ended.

Learning resource center: A location in a hospital or cancer center where patients and families can get information about health-related topics and learn about support resources. Also called a health or hospital library.

Long-term side effects: Side effects that linger after cancer treatment has ended.

Metastasis: Cancer that has spread to other parts of the body from the place where it started.

Oncologist: A doctor who specializes in treating cancer.

Oncology nurse: A nurse who specializes in caring for people with cancer.

Palliative care: Treatments intended to reduce a person's symptoms or treatment-related side effects, improve quality of life, and support patients and their families. Also called supportive care.

Patient navigator: A person, often a nurse or social worker, who helps guide survivors, families, and caregivers through the health care system by offering services such as arranging financial support, coordinating care among several doctors, and providing emotional support.

Patient Protection and Affordable Care

Act: Often called "health care reform," this is a 2010 federal law that changed certain rules regarding health insurance coverage in the United States. Learn more at www.HealthCare.gov.

Physiatrist: A medical doctor who treats injuries and illnesses that affect how a person moves, including the treatment of pain.

Primary cancer: The original (first) cancer with which a person was diagnosed. The primary site is where the cancer began.

Prognosis: Chance of recovery; a prediction of the outcome of a disease.

Psychiatrist: A medical doctor who has special training in preventing, diagnosing, and treating mental, emotional, and behavioral problems.

Psychologist: A specialist who can talk with patients and their families about emotional and personal matters and can help them make decisions.

Quality of life: An overall sense of well-being and satisfaction with life.

Radiation therapy: The use of high-energy x-rays or other particles to destroy cancer cells. Also called radiotherapy.

Recurrence: Cancer that has returned after a period during which the cancer could not be detected. Local recurrence means the cancer has come back in the same general area where the original cancer was located. Regional recurrence refers to cancer that has come back in the lymph nodes or other tissues near the original cancer site. Distant recurrence refers to cancer that has come back and has spread to other parts of the body, usually by traveling through the lymphatic system or bloodstream.

Referral: Recommendation provided by a doctor to get help or information from another health care professional, specialist, or resource. Insurance companies often require a referral before they will cover visits to other health care professionals or specialists.

Rehabilitation: Services and resources that help a person with cancer obtain the best physical, social, psychological, and work-related function during and after cancer treatment. The goal of rehabilitation is to help people regain control over many aspects of their lives and remain as independent and productive as possible.

Remission: Period in which the signs and symptoms of cancer have disappeared. This can be temporary or permanent. Also called “no evidence of disease” or NED.

Secondary cancer: A new primary cancer (a different type of cancer) that develops after treatment for the first type of cancer.

Side effect: An undesirable result of treatment, such as fatigue, diarrhea, or sexual problems.

Social worker: A professional who helps people cope with everyday tasks and challenges before, during, and after treatment. Social workers may work for a hospital, a service agency, or a local government and help address financial problems, explain insurance benefits, provide access to counseling, and more.

Stage: A way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body.

Surgery: The removal of cancerous tissue from the body during an operation.

Targeted therapy: Treatment that targets specific genes, proteins, or other molecules that contribute to cancer growth and survival.

Treatment summary: A written summary of the treatments that a person received for cancer. This is often used with a follow-up care plan to help monitor a survivor’s long-term health.



For more definitions of common cancer related terms, visit www.cancer.net/cancerterms.

Treatment Summary and Survivorship Care Plan

Use these pages to keep track of the major aspects of your cancer treatment and the recommendations for your follow-up care. Please remember, this is not a comprehensive record of your care. Talk with a member of your health care team if you have any questions.

Background Information

Family history of cancer: Yes No

Genetic counseling: Yes No

Genetic/hereditary risk factor(s) or predisposing conditions:

Genetic testing results:

Diagnosis

Cancer type/subtype/location:

Diagnosis date (year):

Stage: I II III IV Not Applicable

Treatment

Surgery: Yes No

Systemic Therapy: Yes No

Surgery date(s) (year): _____

(chemotherapy, hormonal therapy, immunotherapy, other)

Surgery end date(s) (year): _____

Surgical procedure/location/findings:

Name of drug	Start date	End date

Body area treated:

Radiation Therapy: Yes No

Symptoms or side effects that have continued after finishing treatment:

- Buildup of fluid in arms, legs, or neck (lymphedema)
- Change in mood or depression
- Change in weight
- Fatigue
- Heart issues
- Loss of appetite
- Low red blood cell count (anemia)
- Low white blood cell count (neutropenia)

- Memory or concentration loss
- Menopausal symptoms, such as irregular or stopped periods or hot flashes
- Sexual problems
- Skin changes
- Tingling, numbness, or pain in hands/feet (neuropathy)
- Other: _____

My Follow-Up Care Plan

Use this page to help discuss your follow-up care with your doctor and keep track of their recommendations. Talk with a member of your health care team if you have any questions.

Need for ongoing (adjuvant) treatment for cancer: Yes No

Additional treatment name	Purpose	For how long

SCHEDULE OF FOLLOW-UP VISITS

Doctor's name	When/How often

CANCER SURVEILLANCE/OTHER RECOMMENDED TESTS

Test/Procedure	When/How often

It is important to continue to see your primary care doctor for all general health care recommended for a person of your age, including screening tests for other cancers, when appropriate. You should also tell your doctor about:

1. Anything that could be a brand new symptom
2. Anything that continues to be a persistent symptom
3. Anything you are worried about that might be related to the cancer coming back

Signs or symptoms to tell the doctor about right away: _____

Possible late and long-term effects: _____

What concerns do you have as you transition into survivorship?

- | | | |
|---|---|---|
| <input type="checkbox"/> Emotional and mental health | <input type="checkbox"/> Insurance | <input type="checkbox"/> Sexual health |
| <input type="checkbox"/> Fatigue | <input type="checkbox"/> Memory or concentration loss | <input type="checkbox"/> Stopping smoking |
| <input type="checkbox"/> Fertility | <input type="checkbox"/> Parenting | <input type="checkbox"/> Weight changes |
| <input type="checkbox"/> Financial advice or assistance | <input type="checkbox"/> Physical functioning | <input type="checkbox"/> Other: _____ |
| | <input type="checkbox"/> School/Work | |

Looking for More Patient Information Resources?

Visit www.cancer.net/ascoanswers to see all of the available titles in the *ASCO Answers* series.

ASCO Answers Guides are comprehensive booklets, covering survivorship and caregiving. Worksheets and checklists are included.

ASCO Answers Fact Sheets are brief introductions to different cancer types and topics in diagnosis, treatment, and side effects. More than 50 fact sheets are available, including select titles in Spanish.

Patients and Caregivers: For more educational materials, visit www.cancer.net/ascoanswers to find and download all of our available materials.

Oncology Professionals: For free promotional materials for your practice, email contactus@cancer.net.



AMERICAN SOCIETY OF CLINICAL ONCOLOGY
KNOWLEDGE CONQUERS CANCER

AMERICAN SOCIETY OF CLINICAL ONCOLOGY

2318 Mill Road, Suite 800

Alexandria, VA 22314

Phone: 571-483-1300

Fax: 571-366-9530

www.asco.org | www.cancer.net

For more information about ASCO's patient information resources,
call toll-free 888-651-3038 or e-mail contactus@cancer.net.

WE WANT TO HEAR FROM YOU

If you found this material helpful or if you have comments or suggestions
about how it could be better, please let us know at contactus@cancer.net.