



American Society of Clinical Oncology

Making a world of difference in cancer care

Cancer Survivorship

Next Steps for Patients and Their Families

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ABOUT ASCO

The American Society of Clinical Oncology (ASCO) is the world's leading professional organization representing physicians of all oncology subspecialties who care for people with cancer. ASCO's more than 30,000 members from the United States and abroad set the standard for patient care worldwide and lead the fight for more effective cancer treatments, increased funding for clinical and translational research, and, ultimately, cures for the many different types of cancer that strike an estimated 12 million people worldwide each year.



ABOUT CANCER.NET

The best cancer care starts with the best cancer information. Well-informed patients are their own best advocates and invaluable partners for physicians. Cancer.Net (www.cancer.net) brings the expertise and resources of the American Society of Clinical Oncology (ASCO), the voice of the world's cancer physicians, to people living with cancer and those who care for and care about them. All the information and content on Cancer.Net was developed and approved by the cancer doctors who are members of ASCO, making Cancer.Net an up-to-date and trusted resource for cancer information on the Internet. Cancer.Net is supported by the Conquer Cancer Foundation, which provides funding for breakthrough cancer research, professional education, and patient and family support.

Cancer Survivorship

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Introduction

As you complete your cancer treatment, you may be wondering: *what happens next?* The transition to survivorship is unique for each person. The challenge is being able to return to everyday life while adjusting to the changes that result from the disease and its treatment. Recognizing these changes, and knowing how and when to ask for support, can help you through this period of transition.

The American Society of Clinical Oncology (ASCO) is working with oncologists across the globe to help patients and their families achieve the highest quality of life possible after cancer treatment. ASCO is the world's leading professional organization representing doctors who care for people with cancer. The content in this booklet is adapted from ASCO's patient information website, Cancer.Net (www.cancer.net).

Thanks to advances in medical research, the effectiveness of cancer treatment continues to improve. As more people are surviving cancer, how long a person lives is no longer the only focus; it's also important how *well* they are able to live following treatment. The purpose of this booklet is to help survivors and their loved ones prepare for life after treatment. It provides information on issues that can arise, the importance of follow-up care and healthy lifestyle choices, and support options.



About Survivorship

Your life may be forever changed by cancer. Some people talk about appreciating life more and gaining a greater acceptance of self after their cancer treatment ends. Others become anxious about their health and unsure of how to cope with life's demands. In some ways, moving from the period of "active treatment" into survivorship is one of the most complex aspects of the cancer experience because it is different for every person.



Defining Survivorship

Surviving cancer is often defined in several ways. One common definition is a person having no disease after the completion of his or her treatment. Another common definition is the process of living with, through, and beyond cancer. By this definition, cancer survivorship begins when a person is diagnosed. It includes people who continue to have treatment to either reduce the risk of a cancer recurrence (return of cancer after treatment) or to manage the disease over a long time. Using this definition, there are about 12 million survivors in the United States today. Family, friends, and caregivers who have been affected by your diagnosis may also be considered survivors as well.

Different terms can be used to describe the specific periods that a survivor experiences, including:

Acute survivorship—Describes the time when a person is being diagnosed and/or in active treatment for cancer

Extended survivorship—Describes the time right after treatment is completed, usually measured in months

Permanent survivorship—Describes a longer period, often meaning that the passage of time since treatment is measured in years

Some people do not feel comfortable calling themselves a survivor, while others embrace the term. No matter what words you choose, it is

important to define your own path to navigate important changes that often occur during this time.

Survivorship Challenges

During the active treatment period, you likely had many questions. Once treatment is finished, you might be surprised to realize that you have a whole new set of concerns.

This is often a time of mixed emotions. Many people feel relief that their treatment is over. There may also be a surge in anxiety about the future. Some worry that they are not doing enough to actively fight cancer, and others feel nervous about not having the same, frequent contact with the health care team that guided them through treatment. Now that the treatment roadmap is gone, you may not know what to focus on next. You may also be struggling with physical and emotional side effects of treatments.

Every survivor has individual concerns and challenges, but overall, there are some common experiences:

Psychological challenges

Fear of recurrence is very common among survivors. You may feel uneasy that minor physical problems, such as an occasional headache or joint stiffness, may be signs that the cancer has returned. Knowing what is “normal” and what needs to be reported to the doctor is difficult. This feeling usually lessens over time. However, certain events such as your diagnosis anniversary or follow-up exams may make you anxious.

For some survivors, the feeling of uncertainty leads to struggles with depression and anxiety. You may also feel angry or alone, or even have a sense of guilt for surviving when others did not. Some survivors also suffer from poor body image or low self-esteem because cancer treatment changed the way they look. Support groups and counseling can help survivors cope with these and other difficult emotions.

Physical challenges

Cancer and its treatment may cause physical problems, even after treatment ends. Different treatments cause different side effects, and people may experience them differently. In particular, such side effects as fatigue, changes in skin texture, or nerve changes in the fingers

and toes can take months or longer to heal. Some side effects are permanent and require lifelong management. In addition, physical side effects may show up months or years later; these are known as late effects. You may also have another health condition, such as diabetes or heart disease, which has been made worse by the treatment. Some survivors may have had a part of their body altered or removed as part of treatment. To help, there is a wide range of supportive care and rehabilitation services for survivors to cope with any side effects and maximize their physical abilities.

Sexual and reproductive challenges

Some cancer treatments affect a person's sexual and/or reproductive health. If so, you may find it difficult to be intimate with someone, due to physical changes or emotional reasons. If treatment has caused infertility (an inability to produce a child), you may feel grief. You are encouraged to find support as you cope with these changes and losses, either with a health care team member or through print and online resources available about sexual and reproductive side effects.

Relationship challenges

When treatment is over, some survivors need different types of support than they had previously. You may feel that nobody understands the experience you went through. Cancer has had an impact on you and the people close to you; it can change how you relate to them and how they relate to you. Some friends may have become closer, while others have become distant. Families may be overprotective, or they may have exhausted their ability to be supportive. All this may combine to mean that the support you receive after treatment may be different than you had hoped for or expected. At the same time, relationship problems that may have existed before cancer or were put on hold during treatment may resurface. Recognizing and working through these changes are key to helping you get the support you need. A counselor or other health care professional can help you do this.



Work-related challenges

Returning to work is a sign of regaining a normal routine and lifestyle, and most survivors need their job for the paycheck and health insurance it provides. While survivors can be just as productive as they were prior to treatment, some find they are treated differently or unfairly. Or, you may be concerned that asking for help—such as requesting special accommodations—will lead to others thinking that you are less able to do your job. You may feel uncomfortable when asked questions by co-workers about cancer or feel embarrassed about a changed physical appearance.

However, information is available to help you transition back into the workplace, and there are laws and regulations that prohibit discrimination, such as the Americans with Disabilities Act (ADA). People who can help include your employer’s human resources representative and an oncology social worker.



Financial challenges

The cost of cancer care can be high. Even patients with health insurance are left with costs that add up quickly. 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 both medical and household bills. To help, there are national and local organizations that offer financial information, advice, and support. An oncology social worker or patient navigator can connect you with these programs.

Spiritual challenges

Many survivors struggle with questions of why they had cancer and why they survived. For some, spirituality and faith are a source of comfort. Other survivors may find themselves examining long-held beliefs or religious values as they try to make sense of their experience and find new meaning in life. Patients who did not have strong religious or

spiritual beliefs beforehand may have new questions or be confused about what these issues mean to them now. You should feel comfortable reaching out for spiritual support from someone in your religious community or other members of your support network.

Coping with Challenges

With any challenge, a good first step is being able to understand 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 about any concerns you may have is an important part of your follow-up care—especially if a challenge is holding you back from enjoying your life. Just as there were support options during treatment, there is help for you during your transition into survivorship.

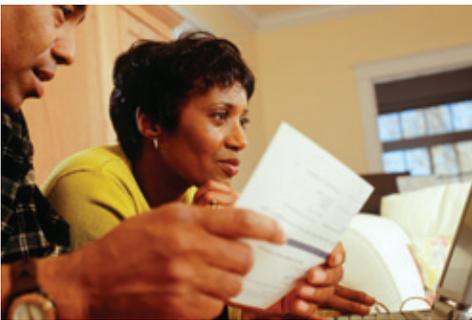
Next Steps After Treatment

As you look ahead to your final cancer treatment, talk with your doctor about the recommendations for your follow-up care. This will include regular physical examinations and/or medical tests to check your recovery during the coming months and years.

Talk with your doctor now about any concerns you have about the future. He or she can give you information and tools to help you right after cancer treatment has ended and in the long term. This is also a good time to decide who will lead your ongoing medical care. Some survivors continue to see their oncologist, while others see their family doctor or another health care professional. This decision depends on several factors, including the type and stage of disease, treatment side effects, health insurance rules, and your personal opinion.

Keeping a Personal Health Record

As time passes, it can be difficult to recall each and every detail of your diagnosis and treatment. At the same time, this information will be very valuable to doctors who care for you throughout your lifetime. A “cancer treatment summary” is a tool that helps store this important information. This report outlines the diagnosis and the treatments you received.



In addition to a record of your cancer treatment, you can ask your doctor for a “survivorship care plan” or “follow-up care plan.” This will describe how often you should return for a check-up and what tests you should have in the future. It will be your guide to monitoring and taking care of your

health, and it can help reduce fear and anxiety. Your doctor will develop your care plan with you based on medical guidelines for your specific disease as well as on your individual needs and choices.

Keep this information in your personal health record, and share it with your current and future health care providers. These details are especially important if your follow-up care will be led by a doctor who

was not involved with your cancer treatment. It gives him or her the information necessary to oversee your survivorship care and to make sure your health is on track.

Although follow-up care is very important, some survivors decide not to follow the recommended plan. Some feel too scared or nervous to schedule regular exams. Others are concerned about the cost of follow-up care or are frustrated by the idea of more tests and examinations. Others simply “feel healthy” and question the need for follow-up. If you have any hesitations about follow-up care, talk with your doctor or other health care professional, instead of skipping a visit or a test. You have worked hard to become a survivor, and follow-up care can help you stay healthy and lead a full life.

ASCO Cancer Treatment Summaries and Survivorship Care Plans

To help you receive post-treatment care, ASCO offers a free set of forms for you to print and bring to your doctor. You and your doctor will work together to complete these forms so you have clear information about your cancer treatment and next steps to take.

ASCO’s Cancer Treatment Summary form and ASCO’s Survivorship Care Plan form record such information as:

- Date of diagnosis and test results
- Type of cancer, including tissue/cell type, stage, and grade
- Type(s) of treatment you had and when, including drug names and doses
- Related medical findings during treatment, such as side effects
- Supportive services provided during your treatment
- Contact information for your cancer care team members
- When and how often you should have physical examinations and/or medical tests
- The risk of your cancer coming back and what signs to look for
- Information on possible side effects that may occur in the future
- Recommendations for healthy behaviors, such as nutritional needs and exercise

To print these forms, visit ASCO’s patient information website at www.cancer.net/treatmentsummaries



The Importance of Follow-up Care

Participating in follow-up care and keeping a medical care support system in place are vital to regaining both your physical and emotional health. It also helps many survivors feel in control as they transition back into their everyday lives.

The first goal of follow-up care is to watch for a recurrence of cancer. In addition, your doctor can identify and address any health issues caused by cancer or its treatment, as well as other health problems. Medical problems found early are more likely to be solved easier than those that are not.

Managing Long-term Side Effects and Late Effects

Most patients experience some type of side effects during the treatment period. However, it is often surprising to survivors that some side effects may linger after treatment is over—called long-term side effects—and that new changes and problems can appear later on. A late effect is a side effect that shows up months or years after treatment ends. If you do experience a long-term or late effect, your doctor and other health care team members will help you treat or manage it.

Cancer treatments are intense, and nearly any treatment can cause long-term and/or late effects. When or if someone is affected varies from person to person. Physical late effects include problems with the heart, lungs, bones, and digestion. Sexual or reproductive health may change. There may also be fatigue, memory problems, and emotional difficulties. Some treatments may cause another type of cancer to occur, called a secondary cancer.

Regular follow-up care is needed to prevent, diagnose, and treat these side effects. And as survivors grow older, late effects can be similar to the normal aspects of aging. It is important to talk with your doctor about what to expect and which screening tests you should have, based on your specific diagnosis and treatment.

Cancer Rehabilitation

In cancer care, rehabilitation is a process that helps a person adjust to and overcome changes due to the effects of cancer or its treatment. Goals may include increasing the ability to move around easily, restoring the body's functioning, and increasing a patient's independence. Rehabilitative services can help a person improve the physical, social, psychological, recreational, educational, and work-related aspects of their lives. Rehabilitation improves many aspects of health, including:

- Physical strength, flexibility, and abilities
- Coping with difficult emotions
- Energy level
- Sense of well-being

Many cancer centers and hospitals offer rehabilitation services and programs. Your health care team will help you identify other local resources. There are also supportive services for a survivor's family members. Support services and resources after treatment include:

Certified health and fitness programs—Provide guidance on regaining strength and getting physically fit



Clinical trials for survivors—Offer the opportunity to participate in research studies focused on improving a person's quality of life after cancer treatment



Family counseling—Focuses on improving family relationships

Genetic counseling—Offers tests and information about your and/or your family's genetics and potential links to cancer

Home care services—Provide physical care to you in your home or help with your basic daily needs

Individual counseling—Helps you understand and work through your personal or emotional concerns

Marriage/couples therapy—Focuses on improving relationships and resolving conflict

Nutritional planning—Provides guidance on your specific nutritional needs, including meal planning, to regain and maintain a healthy weight and lifestyle

Occupational therapy—Helps a person prevent or live with illness, injury, or a disability

Oncology social workers—Provide counseling on ways to cope with a variety of post-treatment issues, including practical, financial, and work-related challenges

Physical therapy—Improves a person's ability to move around and physical functioning and helps prevent further disability

Pain management—Focuses on reducing and relieving cancer-related pain

Recreational therapy—Focuses on reducing stress, anxiety, and depression through games, exercise, arts, crafts, and music

Smoking cessation programs—Provide support and resources for quitting tobacco use

Support groups—Offer a way to share and talk about cancer-related experiences with other survivors in-person or online and receive information and support

Survivor matching programs—Also called buddy programs, these connect survivors who have similar diagnoses, situations, or concerns, to provide peer-to-peer support

Vocational counseling—Helps survivors find or keep a satisfying job

To locate these services, talk with your doctor or local hospitals, call your insurance company, or contact cancer support groups. Many national organizations can also connect you to local resources. In addition, explore www.cancer.net for more information about any of these topics.

Leading a Healthy Lifestyle



For many people, transitioning into survivorship is motivation to make positive lifestyle choices. While healthy habits are a good idea for anyone, they are especially important for survivors. This is because survivors are often at higher risk for other health problems as a result of their cancer treatment. Healthy behaviors can help you regain or build strength, reduce the severity of side effects, lessen the risk for second cancers or other problems, and enjoy your life more.

If you decide to make changes to your lifestyle, set small, achievable goals and work at them each day to help you feel more in control of this change. Remember, it is important to set realistic goals and to recognize that change does not happen overnight. Talk with your doctor or other health care team members about specific lifestyle changes you may want to pursue, such as:

Tobacco cessation

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, make an effort to quit to improve your health overall and to lower your risk of developing a second type of cancer. Be sure to avoid secondhand smoke as well. Many resources are available to help you, including medication and counseling, and can be found at www.cancer.net/tobacco.

Nutrition

Eating well can help people regain strength after cancer treatment and lower the risk for some diseases. It is also key in reaching a healthy weight, particularly if you experienced weight gain or weight loss caused by treatment.

Eat a well-balanced diet that provides the essential nutrients, such as vitamins, minerals, water, protein, and carbohydrates. Many experts

recommend eating plant-based foods, such as fruits, vegetables and grains, and foods low in fat. A dietician can help you understand your own nutritional needs, make healthy eating choices, and create tasty and appropriate meal plans. Ask your doctor for a referral to a registered dietician or visit eatright.org.

Physical activity

Emerging evidence is starting to link exercise with improved quality of life for cancer survivors. Regular physical activity can help survivors increase fitness, manage fatigue, lose or maintain weight, improve heart health, manage stress, and improve mood and self-esteem. It also reduces the risk of high blood pressure, heart disease, stroke, and diabetes.

Talk with your doctor before you start an exercise program, because you may need to adapt what kinds of exercises you do to your specific needs and limitations. The American College of Sports Medicine recommends that survivors avoid inactivity and, to the extent possible, get regular physical activity including at least 150 minutes of moderate aerobic activity weekly and resistance (strength) training two or three days per week. Start slow, and remember, even a small amount of physical activity is helpful. A certified health and fitness professional can help you develop a plan based on your doctor's recommendations.

Complementary therapies

Complementary medicine is a general term used to describe therapies, techniques, and products that are not considered to be part of conventional medical care. A few examples include acupuncture, yoga, massage, and relaxation techniques. Many complementary therapies can be safely used to manage long-term or late effects or improve a person's physical or emotional well-being. However, you should be sure that it does not change your conventional medical care. For instance, some dietary and herbal supplements interfere with specific medications. Before starting any complementary therapy, talk about it with your doctor, and get a referral to a qualified provider.

Stress reduction

A serious disease such as cancer is very stressful. Everyday life often adds to your stress level, too. Chronic stress may cause health problems and decreased feelings of well-being.

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 time or energy to complete, doing your most important tasks first, and getting help with such challenging issues as finances. Other ways to manage stress include exercise, social activities, support groups, and some complementary therapies. Many relaxation techniques can be learned in a few sessions with a counselor or in a class.



Relationship building

Cancer often changes the way you relate to your family, significant others, and friends, and the way they relate to you. Many people do not know what to say or how to act when someone has finished treatment. Make time to reconnect with those you care about. Set simple goals like enjoying a shared experience, such as watching a television show or going for a walk. Some survivors meet new people—and get a sense of satisfaction and fulfillment—through support groups or by participating in a new activity unrelated to cancer.

Giving back

Positive feelings are often set in motion during the transition to survivorship. Many survivors express a strong desire to “give something back” due to the good care and kindness they received. This may result in such action as volunteering at a cancer center, joining a patient advocate group, enrolling in a cancer registry or research study for survivors, donating money, or helping raise funds for research. Survivors often report they gain a sense of personal fulfillment and accomplishment through such activities because they are focused on helping others.

Questions to Ask



Talking with your health care team about the specific plan for your survivorship care is important. And, never be afraid or embarrassed to ask your doctor for help with a particular concern. Your doctor may not have all of the answers to your questions but can give you resources to help you get the best possible information. Several people and groups will likely help you find answers, including doctors and their support staff, nurses, social workers, other health care professionals, and patient advocacy organizations.

Use the list of questions below to help focus your conversation. **You don't need to ask every question—just choose the ones that are most important to you.** Remember: these talks between you and your health care team should continue throughout your lifetime.

Health-related concerns

- How likely is it that the cancer will return?
- What signs or symptoms should I report to you right away? What should I report at my regular follow-up visits?
- What can I do to lower my risk of the cancer coming back?
- What is my risk of developing another type of cancer?
- Who will be overseeing my post-treatment medical care?
- Where will I be receiving my survivorship care?
- How often should I return to see you for follow-up exams?
- What follow-up tests will I need? How often?
- What screening tests do you recommend, given the treatment I had? For how long?
- Are there late effects I should watch for? What should I do if I notice a late effect?
- Can I get a written summary of my cancer treatment and a survivorship care plan for my records?
- Do I need to take any special medications or follow a special diet?
- Are there programs that can help cover the costs of drugs I still need?
- Would I benefit from cancer rehabilitation services? If so, what type?
- What type of physical activity would you recommend for me?

- If I have difficulties related to my sexual or reproductive health due to my cancer treatment, who can help me?
- What can I do to support my emotional health?
- Are there clinical trials about survivorship care that I should consider?
- Could I benefit from genetic counseling and testing? Should my family members consider this as well?
- Are there groups or online resources you'd recommend that can help me learn about survivorship after my specific diagnosis?

Financial concerns

- If I am having difficulty paying my medical bills, are there organizations that can help me?
- 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 me?
- Where can I get free or low-cost personal items after treatment, such as medical supplies, if needed?

Health insurance concerns

- How many medical bills do I still have left to receive related to my active treatment period?
- Who can help me understand what my insurance will cover in terms of my recommended survivorship care plan, such as follow-up exams and medical tests?
- If an insurance claim is denied, who can help me file an appeal?
- If I'm thinking about switching health insurance plans, what do I need to know about the current rules about pre-existing conditions and/or waiting periods for coverage?

Employment and legal concerns

- If I am nervous or feel overwhelmed about returning to work, who can help me?
- If I have difficulty talking with my co-workers about my cancer experience, what are some coping strategies I can try?
- What information do I need to give my employer upon returning 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?
- Where can I find out if my medical and related expenses can be deducted from federal income taxes?

Survivorship Resources

The following national organizations provide a wide range of resources for cancer survivors and their families. Contact these organizations directly to learn more about their specific programs and services, including eligibility criteria. In addition, many patient advocate organizations offer survivorship services for people with a specific diagnosis. Because programs and services continually change, this list is not inclusive and readers are encouraged to visit ASCO's patient information website, Cancer.Net (www.cancer.net), to get more information about support options.

American Institute for Cancer Research

www.aicr.org/patients-survivors/
800-843-8114

Cancer and Careers

www.cancerandcareers.org

CancerCare

www.cancercare.org
800-813-4673

Cancer Financial Assistance Coalition

www.cancerfac.org

Cancer Legal Resource Center

www.cancerlegalresourcecenter.org
866-843-2572

Cancer Support Community

www.thewellnesscommunity.org
202-659-9709

Job Accommodation Network

<http://askjan.org>
800-526-7234

Journey Forward

www.journeyforward.org

LIVESTRONG

www.livestrong.org
855-220-7777

MyOncofertility.org

<http://myoncofertility.org>
866-708-3378

National Coalition for Cancer Survivorship

www.canceradvocacy.org
888-650-9127

National Cancer Survivors Day Foundation

www.ncsdf.org

National Cancer Institute: Office of Cancer Survivorship

<http://survivorship.cancer.gov>
800-422-6237

Patient Advocate Foundation

www.patientadvocate.org
800-532-5274

Online Support Communities

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. They provide support, information, and an outlet for sharing your feelings. In addition, they can be a valuable resource to survivors who live far from an in-person support group, and give people who don't like face-to-face groups another way to seek support. Many cancer advocacy organizations have online support groups as well. If you have thought about joining an online community, here are a few options to explore:

**American Cancer Society:
Cancer Survivors Network**
www.acscsn.org

CarePages
www.carepages.com

CaringBridge
www.caringbridge.org

I Had Cancer
www.ihadcancer.com

Inspire
www.inspire.com

LIVESTRONG.com
www.livestrong.com

Age-Specific Resources

There are also many resources to help cancer survivors based on your age at the time of your diagnosis or your age now. These are often divided into four main categories: childhood, adolescents/teenagers, young adults, and older adults. These resources tailor coping techniques and support programs to meet the unique physical, social, and emotional needs at each stage of life. Ask your health care team or visit www.cancer.net for more information about age-specific resources that may benefit you.

MyLifeLine.org
www.mylifeline.org

Navigating Cancer
www.navigatingcancer.com

Peer Support Network
www.peersupportnetwork.org

Glossary

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.

ADA—The Americans with Disabilities Act. A national law that doesn't allow discrimination against people with disabilities. It requires employers to make reasonable accommodations in the workplace for qualified individuals with a disability. Learn more at www.dol.gov.

Anxiety—Feelings of nervousness, fear, apprehension, and worrying.

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.

Cure—To fully restore health. This term is sometimes used when a person's cancer has not returned for at least five years after treatment. However, some doctors do not use this term because undetectable cancer cells may remain in the body after treatment, causing the cancer to return later (called recurrence), even after five years.

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

Disease-free survival—The length of time after treatment during which no sign of cancer is found. This term can be used for an individual or for a group of people within a study.

Event-free survival—The length of time after treatment that a group of people in a clinical trial has not had cancer come back or get worse. This term is usually used only in scientific research.

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

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

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

Permanent survivorship—A term describing a longer period since treatment has ended, often meaning that the passage of time since treatment is measured in years. Also called long-term survivorship.

Physiatrist—A medical doctor who treats injuries and illnesses that affect how you move, including the treatment of pain. Also called a rehabilitation specialist.

Pre-existing condition—A medical condition that a person already has when enrolling in a new health insurance plan. Many health plans have a specific period of time in which they will deny all claims related to pre-existing conditions, although these are governed by federal rules. Learn more at healthcare.gov.

Progression-free survival—The length of time during and after treatment that the cancer does not grow or spread further. This term is commonly used in scientific research studies.

Primary cancer—In survivorship care, this means the original (first) cancer with which you were diagnosed.

Psychologist/psychiatrist—Mental health professionals who work to address a person's emotional, psychological, and behavioral needs.

Quality of life—The overall sense of well-being and satisfaction with life.

Recurrence—Cancer that has returned after a period during which the cancer could not be detected. “Local recurrence” means that the cancer has come back to 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 (metastasized) to other parts of the body, usually by traveling through the lymph system or bloodstream.

Relative survival—The length of time after treatment that a person with cancer lives, excluding all other causes of death. This term is commonly used in scientific research studies.

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

Secondary cancer—This is a different type of cancer that was caused by the treatment of the primary (first) cancer.

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.

Supportive care—Treatments that relieve side effects of treatment and improve a patient’s quality of life. Also called palliative care, symptom management, and side effects management.



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