

NCCS Articles

Whether newly diagnosed, currently in treatment, or living for many years or decades, people with a diagnosis of cancer face a host of challenges that fall under the term “cancer survivorship.” The following ten articles written by the National Coalition for Cancer Survivorship cover a range of important topics for individuals who are living with, through, and beyond cancer.

- [Speak Up for Yourself!](#)
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- [Develop a Cancer Care Plan](#)
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Speak Up For Yourself!

For people living with problems related to cancer, effective communication is critical. It's important to talk about your cancer in a way that helps others understand your needs and wishes. So how do you put that into practice? How do you communicate clearly and speak up—or advocate—for your own needs with your health care team and with concerned family members and friends?

During this stressful period, consider these five basic skills:

- 1** Assert yourself. Be clear with others that what you have to say is important.
- 2** Use “I” messages. Make statements with “I” in them, such as “I think” or “I feel.” This is about you. Be your own advocate.
- 3** Listen actively. Make sure that the person to whom you're speaking knows that you are listening carefully—then check to make sure that what you heard is really what the person meant to say.
- 4** Match what you say in words to your body language. For example, you may confuse people if your facial expressions send a message different from what your words are trying to convey.
- 5** Share your emotions. Express your hopes, fears, and concerns with those who are in a position to be helpful to you.

Communicate with Your Health Care Team

Establishing a good relationship with your health care providers is vital. Patience, mutual respect, and a shared understanding of each person's role are key elements. The following are a number of ways you can advocate for yourself and ensure that you are communicating effectively.

- Tell your doctor how much you want to know about your illness. Some people do not wish to know all the details, and some want all available information.
- If you want to be more fully involved in your care, let your doctor or nurse know that you accept responsibility for shared decision-making and want to work in partnership with your health care team.
- Come to your appointments prepared with questions for your doctor and information about how you are feeling. If possible, have someone accompany you to appointments.

This person can take notes and provide feedback about the meeting. If you cannot take someone with you, ask if you can tape the conversation. If you are keeping records about your condition bring them with you to your appointment. It is also helpful to bring a list of medications you are taking that were not prescribed by your oncologist.

- Keep asking questions until you fully understand what your doctor has said. You can't be expected to "get it" all in one explanation, and you may have to ask for clarification several times. Be sure you know whom to call with questions or concerns that arise between visits.
- If you would like to communicate via e-mail, ask if your doctor welcomes that type of communication. Be mindful that important messages should be delivered in person or over the phone—this will ensure the timeliest response.
- If you feel that you and your doctor are not communicating well, discuss this openly. You may find some straightforward solutions, like asking to schedule time to talk further if your doctor seems rushed during your visit.

- Finally, remember that mutual respect is the hallmark of all good relationships—and when you have cancer, a satisfying doctor/patient relationship is essential. Your health care team is there to ensure that you'll always receive the information you need to make informed decisions about your care.

Communicate with Family Members

Speaking with your family members and well-meaning friends can be more stressful than communicating with your health care team. Your family and friends have the greatest investment in your well-being, yet they may be fearful of saying the wrong thing or, in some cases, second-guessing your decisions. At the same time, many cancer patients withhold information because they don't want others to worry, or they simply expect family members to know what to say or do.

With these relationships, the key is to express what you want and need—while doing your best to understand what others are thinking and feeling. If you prefer not to share some details, be clear about your wishes. On the other hand, if you want a certain level of support, make that clear. Everyone benefits from effective communication and an understanding of your needs.



Resources

NATIONAL COALITION OF CANCER
SURVIVORSHIP

“Cancer Survival Toolbox”

www.canceradvocacy.org/toolbox

Visit the following sections:

Communicating, Standing Up

For Your Rights, Making Decisions.

“First Steps”

[www.canceradvocacy.org/resources/
treatment-issues/first-steps.html](http://www.canceradvocacy.org/resources/treatment-issues/first-steps.html)

“Teamwork: The Cancer Patient’s Guide To
Talking With Your Doctor”

[www.canceradvocacy.org/resources/
publications/teamwork.pdf](http://www.canceradvocacy.org/resources/publications/teamwork.pdf)

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Navigate Your Treatment Options

When you are diagnosed with cancer, it is essential to be sure the diagnosis is correct. In many cases, your first step will be to get a second opinion about the pathology of the cancer. Once the diagnosis is confirmed, the next decisions you make are among the most important, because they set the course for the management of your cancer.

Following the diagnosis, you will likely receive a referral to a physician who specializes in cancer care—most often a medical oncologist or hematologist. There is seldom only one treatment option. In fact, for most cancers, there are several equally effective treatment options to consider. For some cancers, referrals to cancer centers or to oncologists who participate in cancer clinical research trials may be your best choice, so one of the questions you should ask is if there are any clinical trials that would be appropriate for you to consider. (Visit www.cancertrialshelp.org/trialcheck/ for more information about clinical trials.) Understanding all your options can be overwhelming, but it's very important that you be involved and know what questions to ask. (See Resources. Examples of the kinds of questions to ask your doctor are included on the NCCS Web site in the *How to Make Your Decisions* section.)

Take an Active Role in Decisions about Your Treatment Options

Even if you're comfortable allowing your doctor to make decisions for you, there are good reasons why you should take the lead in deciding about your care.

First, making a shared decision with your doctor about treatment will help you become a better advocate for your needs. Moreover, playing an active role in your own care can have both physical and emotional benefits. Studies of cancer survivors show that those who are active in making decisions about their cancer treatment tend to manage the side effects of treatment better than those who have little or no knowledge or remain passive about their cancer.

How to Make Your Decisions

It may be helpful to think of the process of choosing a treatment plan as a series of steps:

- Establish how much time you have to make a decision
- Learn your options
- Weigh the pros and cons for each treatment option
- Consider your own personal situation and the impact each choice is likely to have on your life
- Decide on a course of action

Before you begin discussing options, you should be clear on an important issue: How quickly must you decide on a treatment plan? Do you have time to do more research and talk things over with others, or must you act immediately? Whether your answers bring you more pressure or less, you need to know the time frame for your decision.

Your next step will be to discuss your available treatment options. As your doctor explains each one, here are some questions to raise:

- How successful has this treatment been for other patients?
- What are the pros and cons of this choice?
- What side effects will I be likely to experience during this treatment?
- What long-term effects might occur after treatment has ended?
- What changes can I expect in my lifestyle during treatment?
- Will I or my caregivers need to be aware of any extra care I might require during treatment?
- Does the treatment facility routinely deliver this type of care?
- Will my insurance cover the costs of this treatment? Will there likely be additional services I'll need that my insurance does not cover?

In addition to the treatments your doctor outlines, you may also want to explore two other options: the availability of a clinical trial, which compares a new treatment to a standard treatment being offered by your physician,

and whether there are complementary options that you could use along with your primary treatment. These might include such approaches as massage therapy, nutritional changes, acupuncture, and others.

Keep in mind that you can always seek a second opinion from another doctor. This does not indicate a lack of respect for your doctor—only a desire to thoroughly examine your options.

Weighing Pros and Cons

Every treatment option has positive and negative aspects. Weighing those pros and cons is a necessary step in deciding which option to choose.

Some of the biggest questions that people have are, “What are my chances of recovery if I choose this treatment over another?” Or, “How much longer can I expect to live if I choose this treatment over another?”

Some doctors respond to this by citing statistics that help you understand the effectiveness of the recommended treatment. Statistical information, sometimes called “data” or “evidence,” can help you sort out your treatment options. But remember that statistics only show what has happened in general in large groups of cancer survivors. Gather the information you feel you need, understand the time you have to make your decision, and let all the pros and cons (including the best available data and your personal circumstances) guide you.



Resources

NATIONAL COALITION OF CANCER SURVIVORSHIP

“Cancer Survival Toolbox”

www.canceradvocacy.org/toolbox

Visit the following section: *Making Decisions*.

“First Steps”

www.canceradvocacy.org/resources/treatment-issues/first-steps.html

COALITION OF CANCER COOPERATIVE GROUPS

www.cancertrialshelp.org/trialcheck

Information about clinical trials.

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Treat Your Whole Self, Not Just Your Cancer Cells

When you are diagnosed with cancer, the primary concern for you and your doctor is getting rid of the cancer. That is obviously the most crucial aspect of your doctor's role, but it is only one part of caring for you. As a cancer patient, you need care as a “whole person,” which includes the emotional challenges that come with a cancer diagnosis and the life challenges that have an impact on your quality of care—and quality of life.

Emotional Support

Coping with cancer can be a difficult journey, emotionally as well as physically. Stress and strain and some degree of anxiety or depression are common for cancer patients and their caregivers. People with cancer can benefit from having an assessment of their emotional adjustment to the diagnosis. Be sure to ask your doctor or nurse to evaluate your symptoms to determine if you would benefit from psychosocial support and/or medical interventions geared to dealing with those symptoms.

If your health care team does not ask about your emotional well-being, do not hesitate to raise the issue yourself. Addressing your psychological needs is an essential part of providing quality care and improving your overall health.

Most cancer treatment facilities have specialists in psychosocial oncology available. These may be psychologists, psychiatrists, or social workers experienced in negotiating the challenges cancer brings to patients' lives. Most doctors who treat cancer also work with such professionals, as well as with nurses, chaplains, and counselors experienced in managing cancer-related issues.

Working with a mental health professional usually involves a series of private conversations to discuss your feelings about your cancer and how it affects your life, accompanied or followed by a variety of treatment approaches that may include counseling sessions, relaxation exercises, and medication according to your specific needs.

You may also consider joining a support group, which can provide information, emotional support, coping skills, and a way of reducing anxiety and fear. Support groups, conducted in

person and online, have helped many people with cancer gain the support and strength they need to cope with the disease. Additionally, research has shown that patient support groups improve the quality of life for many people.

Social and Practical Needs

Many in the healthcare professions understand that dealing with cancer treatment and the life challenges it presents can be just as difficult as fighting the disease itself. For example, you can't get first-rate health care if you don't have transportation to your appointments. You won't take the prescription medications you need if you can't afford them. And you can't return to health—and a high quality of life—if you are unable to take care of your daily personal needs, like bathing, preparing meals, and performing household chores.

Fortunately, many organizations—government, nonprofit, religious, and community volunteer groups—are available to help cancer survivors meet these important needs. Often the services are free. If you need help and don't know how to find it, ask your health care team or the oncology social worker at your treatment center for advice and referrals.

Advocate for Yourself

Don't assume that family members, friends, caregivers, or even your health care team know what you think, feel, or need. A key component of getting treatment for yourself as a “whole person” is self-advocacy—speaking up for what you need in order to cope with the physical and psychological effects of cancer and its treatment, and to live your day-to-day life.



Resources:

INSTITUTE OF MEDICINE, OCTOBER 2007

“Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs—Resources,”
www.iom.edu/Object.File/Master/47/604/Whole%20Cancer%20Resource%20List%20and%20Role%20Models.pdf

NATIONAL COALITION OF CANCER SURVIVORSHIP

“Resource Guide”
www.canceradvocacy.org/resources/guide/

“Self-Advocacy: A Cancer Survivor’s Handbook”
www.canceradvocacy.org/resources/publications/advocacy.pdf

“Treatment Issues: Pain”
www.canceradvocacy.org/resources/treatment-issues/pain/

“Treatment Issues: Side effects”
www.canceradvocacy.org/resources/treatment-issues/side-effects/

“Helping with Emotional Issues”
www.canceradvocacy.org/resources/special-topics/caregiving/emotional.html

“Issues of the Heart and Mind”
www.canceradvocacy.org/resources/treatment-issues/heart-mind/

“You Have the Right to Be Hopeful”
www.canceradvocacy.org/resources/publications/hopeful.pdf

THE WELLNESS COMMUNITY

www.thewellnesscommunity.org
Information about support and education for people affected by cancer.

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Develop a Cancer Care Plan

Receiving a diagnosis of cancer is the beginning of a journey with two major stages: the first starts with your cancer treatment, and the second begins when your treatment ends and you transition to “life after cancer.” Developing care plans for both of these stages will help you receive comprehensive and coordinated health care throughout your life as a cancer survivor. The following will give you an idea of what to request from your care team, but you should be aware that efforts to implement systems of care planning before and after cancer treatment are new and not yet common practice, so a cooperative and flexible approach by both parties (you and your care team) will be valuable.

Planning for Your Treatment

If you are newly diagnosed, receiving a written plan for your treatment (**Cancer Care Plan**) will help you in many ways. For example, a written plan will give you a full view of the information that will enable you to ask questions and have a thorough discussion with your doctor, including potential side effects you should expect from treatment and how they will be addressed.

If you have more than one treatment option to consider, a written care plan may help you and your doctor discuss the pros and cons of each. A written care plan also can make it easier for you share details about your upcoming treatment with family members and caregivers so they, too, have a better idea of what to expect. Family and friends may help you think of additional questions to pose to your doctor before treatment begins.

Care plans are key to good management of cancer care. They improve communication between you and your physician and allow you to participate more fully in decisions related to your care. Your care plan can be used to coordinate your overall care, including not just your cancer treatment and its side effects, but also your social and emotional needs.

Planning for Your Future Health

Your need for care does not end with your last day of treatment. A diagnosis of cancer changes your health care needs for the rest of your life. As a cancer survivor you may face challenges in the years following your treatment, including:

- Cancer recurrence: a reappearance of the original cancer
- Second cancer: development of a new and entirely different cancer

- Organ damage: the effects of treatment on the heart, lungs, ovaries, testicles, bone marrow, and other organs
- Emotional and social issues: some of the most common include stress and depression, employment discrimination, fertility issues, and access to adequate health insurance

Although research in the field of cancer survivorship is underway, little is currently known about how to diagnose, prevent, and screen for the late effects of cancer and its treatment. This means that it is extremely important for you to be a strong advocate for your own good health care.

Upon completing treatment, you should request a formal consultation with your doctor and ask him or her for a **Cancer Treatment Summary** (a complete and detailed summary of your diagnosis and treatment) and a **Survivorship Care Plan** (a plan for lifelong follow-up care after your primary cancer treatment).

This is a relatively new practice for oncologists. The American Society of Clinical Oncology (ASCO) has created templates for physicians to use. (See Resources.) If your doctor is not using a template from ASCO or elsewhere, request that your Cancer Treatment Summary and Survivorship Care Plan include:

- Your cancer diagnosis, tumor characteristics, diagnostic tests performed, treatments received (including surgeries, chemotherapy, radiotherapy, names of drugs and dosages administered) and supportive services (including psychological and nutritional) you've made use of

- Dates for all diagnoses and treatments
- Potential late- and long-term effects of the treatments you received
- Specific information about the timing and content of recommended follow-up (for example, screening tests for recurrences and/or secondary cancers, follow-up visits with your oncologist, etc.)
- Recommendations about preventive practices and how to maintain health and well-being (for example, nutrition, exercise, and emotional support)
- Complete contact information for members of your health care team
- A single point of contact for coordinating your continuing care

During the consultation, ask your doctor or nurse to explain the Cancer Care Summary and Survivorship Care Plan to you. It is important that you understand these documents. You should keep them in a safe place where you store other important personal records. Be sure to give copies to the health care providers who examine you in the months and years to come.



Resources

NATIONAL COALITION OF CANCER SURVIVORSHIP

“Survivorship Care Planning”

www.canceradvocacy.org/care-plans.html

“Your Life After Cancer Treatment”

[www.canceradvocacy.org/
resources/publications/brochures/
life-after-treatment.pdf](http://www.canceradvocacy.org/resources/publications/brochures/life-after-treatment.pdf)

INSTITUTE OF MEDICINE

“Cancer Survivorship Care Planning,” Fact Sheet, November 2005 [http://iom.edu/
CMS/28312/4931/30869.aspx](http://iom.edu/CMS/28312/4931/30869.aspx)

“From Cancer Patient to Cancer Survivor: Lost in Transition,” Institute of Medicine, November 2005. [http://iom.edu/CMS/28312/
4931/30869.aspx](http://iom.edu/CMS/28312/4931/30869.aspx)

AMERICAN SOCIETY OF CLINICAL ONCOLOGY

“Cancer Treatment Summaries”

[www.plwc.org/portal/site/PLWC/
menuitem.034b98abc65a8f566343cc10ee37a01d/
?vgnextoid=112abfbefabe5110VgnVCM100000ed73oad1
RCRD](http://www.plwc.org/portal/site/PLWC/menuitem.034b98abc65a8f566343cc10ee37a01d/?vgnextoid=112abfbefabe5110VgnVCM100000ed73oad1RCRD)

“Expert Corner: ASCO Cancer Treatment Plans and Summaries”

[www.plwc.org/portal/site/PLWC/
menuitem.169f5d85214941ccfd748f68ee37a01
d/?vgnextoid=4f97b6812e1e5110VgnVCM1000
00ed73oad1RCRD&vgnnextchannel=9b7903e84
48d9010VgnVCM100000f273oad1RCRD](http://www.plwc.org/portal/site/PLWC/menuitem.169f5d85214941ccfd748f68ee37a01d/?vgnextoid=4f97b6812e1e5110VgnVCM100000ed73oad1RCRD&vgnnextchannel=9b7903e8448d9010VgnVCM100000f273oad1RCRD)

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Get the Most from Your Insurance Coverage

With a diagnosis of cancer, you may start thinking about health insurance in a new light. Chances are you will rely on your health insurance more than you ever needed to before. Therefore, it is critical that you know and understand your rights and responsibilities under your health insurance plan.

Understanding Your Insurance Policy

Insurance information confounds many people, and when you are diagnosed with cancer, you may feel overwhelmed at having to negotiate coverage with your insurance company. This might be a task you'll share with a family member or friend who wants to support you. The first step is to read your policy from beginning to end so you understand what coverage you have and how to use it. Learn about your policy's deductibles, co-pays, out-of-pocket expenses, and lifetime maximums. Confirm any pre-authorization or certification requirements you will have to meet. And understand your plan's coverage for experimental therapies and clinical trials as well as complementary options such as acupuncture and massage therapy. If you have questions about your policy, reach out to the experts available to help you. These include:

- Customer service representatives at your insurance company
- Social workers, case managers, or financial counselors at your hospital or treatment center

- Human resources professionals where you work

One benefit that may not be explained in writing is a service offered as part of the major illness/catastrophic illness portion of most health plans: case management services. The case manager is your personal contact at the insurance company; he or she will work with you to ensure that your questions about your coverage are answered and your needs are met. When you call to request this assistance, an intake person will take your basic information, including your diagnosis, so you can be assigned to a cancer specialist.

Using Your Insurance

When you start submitting claims to your health insurance provider, remember a few guidelines:

Follow your insurer's rules. You might, for example, be restricted to a network of doctors or hospitals. Going out of network often means you will have to pay more or that the plan will

deny your claim outright. You may need to get permission (a referral) to see a specialist or to get a lab test. You might need to submit claims within a certain number of days of your appointment or treatment. Following your insurer's rules will maximize your coverage and minimize your out-of-pocket expenses.

Keep good records, including copies of all bills and correspondence. Ask for names, titles, addresses, and phone numbers when you talk to people about your bills, and note key points and the dates of your conversations. Establish a file or notebook where you keep all your materials. It is a good idea to keep all original bills for follow-up purposes.

Submit your claims on time and in chronological order. Most insurance companies have a time limit for submitting claims. It could be one year from the date of service, or by the end of the calendar year. Make sure you know your policy's time limits. If you have more than one policy, you must send the right bills to the right company at the right time.

Don't Take "No" for an Answer

If one of your claims is denied, appeal it. Send the claim back again and again if necessary, and consider asking your doctor to help you make your case, either in writing or by calling the medical director of your health plan.

Keep records of all your correspondence. And again, be aware of any time deadlines that might apply. Sometimes you can only appeal a denial within a certain number of days following the decision.

Finally, if all else fails and your insurance carrier will not reverse its denial of a claim, you may be able to appeal to an outside panel of experts. Insurance regulators in a growing number of states are making this an option for cancer patients who believe they are not being treated fairly.

Resources

NATIONAL COALITION OF CANCER SURVIVORSHIP

"What Cancer Survivors Need to Know About Health Insurance"

www.canceradvocacy.org/resources/publications/insurance.pdf

"Insurance"

www.canceradvocacy.org/resources/insurance.html

"Cancer Survival Toolbox"

www.canceradvocacy.org/toolbox

Visit the following section:

Finding Ways to Pay for Care.

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Cancer and Work

Cancer will affect at least one in three Americans during their lifetimes. While medical care is essential for people with cancer, it is often just as important for them to maintain as normal a life as possible to speed recovery. For many, this means going to work and participating in the same activities as they did prior to diagnosis.

Talking to Your Employer

When, how, and what you tell your employer about your cancer diagnosis and treatment is a personal decision. If you do decide to share details with your employer or supervisor, be prepared to discuss how your treatment will affect you in your job and what sort of accommodations, including time off, you may need. Having the answers to the following questions (which you can cover with your doctor ahead of time) may help you have a productive conversation.

- How will your treatment and recovery affect your ability to do your job?
- How much time will you need to take off?
- Will you be able to continue to do your job as well as you did before you were diagnosed with cancer?
- When can you expect to return to your “before cancer” work status?

Although your employer will most likely support you during your treatment, it is a good idea to keep a record of any talks you conduct with your manager and people in the human resources or benefits offices. Also keep copies of performance reviews, memos, and letters regarding your employment and requests

for benefits such as disability. This sort of documentation will help you if you ever need to take action in the future.

Job Challenges Faced by Cancer Survivors

While most employers treat cancer survivors fairly and legally, some—due either to outdated personnel policies or an uninformed or misguided supervisor—erect unnecessary and sometimes illegal barriers to survivors’ job opportunities. People who have faced cancer can encounter problems such as dismissal, failure to be hired, demotion, denial of promotion, denial of benefits, undesirable transfer, and hostility by coworkers.

Cancer survivors are at times treated unfairly because some people still believe myths about cancer that lead them to make wrong assumptions about cancer survivors’ ability to work. These myths include:

- that cancer is a death sentence. In reality, more than 60 percent of individuals diagnosed today will live through and beyond cancer.
- that a cancer diagnosis or cancer history will cause group insurance premiums to

increase. In reality, one person's illness is unlikely to affect group insurance costs dramatically unless the policy covers only a small number of workers.

- that cancer survivors are unproductive workers. In reality, studies show that most adult survivors return to work after their diagnoses and have productivity rates similar to those of other workers.

Employers as well as fellow employees may believe myths and may stigmatize workers with cancer. The keys to changing these harmful beliefs are education and communication.

Protecting Your Rights

Cancer patients have many legal protections in the workplace. Under federal law and many state laws, for example, an employer cannot treat you differently from other workers in job-related activities because of your cancer history as long as you are qualified for the job. And employers also must provide "reasonable accommodations," such as a change in work hours or duties, to help you do your job during or after cancer treatment.

Provisions in the Family and Medical Leave Act (FMLA) of 1993 require that businesses with 50 or more employees allow them up to 12 weeks of unpaid leave during any 12-month period for certain circumstances, including a serious illness. This could be an important option for you if your treatment prevents you from

working. If you take this leave, your employer must continue to provide benefits—including health insurance—while you are away, and must place you in the same or an equivalent position when you return.

While these laws discourage job discrimination, they can't prevent it. If you face discrimination, you must decide how to take action. Your first step should be to attempt a reasonable settlement with your employer. This may take several forms. But if you don't get the fair treatment you deserve, the remedy of last resort may be to consult an attorney—which is a decision that should be considered very carefully.

Resources

NATIONAL COALITION FOR CANCER SURVIVORSHIP

"Working It Out: Your Employment Rights as a Cancer Survivor"

www.canceradvocacy.org/resources/publications/employment.pdf

"Coping With Your Employer"

www.canceradvocacy.org/resources/special-topics/caregiving/employer.html

"Employment"

www.canceradvocacy.org/resources/employment.html

"Cancer Survival Toolbox"

www.canceradvocacy.org/toolbox

Visit the following section: *Living Beyond Cancer*.

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Find Financial Assistance

Cancer can have a devastating financial impact on survivors and their families. Even if you have good health insurance coverage, your direct medical costs and related nonmedical expenses can quickly add up.

Most direct medical costs resulting from cancer treatment (such as physicians' fees, hospital expenses, and pharmacy bills) are covered at least in part by basic health insurance plans. But your insurance policy may not cover every aspect of your treatment, and you will be responsible for deductibles and co-pays. If your policy has deductibles and co-pay, ask your physician to give you a preliminary estimate of the expected out-of-pocket costs.

Some of the nonmedical expenses you may incur include transportation to and from treatment, child care, a nurse's aide, a housekeeper, a counselor (such as a social worker or psychologist), and treatment-related consumer products (such as a wig).

Cancer can take an especially severe financial toll on patients who are unable to work, do not have adequate health insurance, or do not have savings or other financial resources. The cost of cancer care is particularly high for those who require expensive long-term care, including rehabilitation or long stays in a hospital or nursing home.

Another financial challenge may be the delay in review by your insurance company or disability provider. It is not uncommon for reviews to take several months, so it is important that you develop a short-term plan while getting the reviews done.

Managing Your Bills

If you are having trouble managing all your expenses, you may want to contact a financial counselor to help you plan a budget. Look in the telephone directory under "consumer credit counseling services" for a nonprofit service that can help you manage your bills. A nonprofit service is likely to offer free or inexpensive assistance; a for-profit company will charge you a fee for its service.

If you cannot locate a nonprofit service in your community, contact the National Foundation for Credit Counseling (800-388-2227, www.nfcc.org) for the name of a credit counseling service in your area.

Where to Turn for Help

If the cost of cancer care exceeds your resources, don't hesitate to contact one of the many private organizations that provide financial support for medical care and related expenses. For example, some organizations have programs that arrange free transportation to and from treatment. Others supply "lending libraries" of wigs, hospital beds, wheelchairs, and related products. Some organizations offer stipends to families who cannot pay their bills.

The type and amount of financial assistance available varies from community to community. Many of these services are not advertised, but are available for the asking.

You can learn about financial help in your community by contacting the social work department of your hospital, a cancer resource center, a local cancer organization, your labor union, your local congressional representative's office, and local community service, religious, and social organizations. Below is a list to get you started.

Private Sources of Information and Financial Assistance

CancerCare (800-813-4673, www.cancercares.org) is a nonprofit organization that provides free guidance, information, and referrals to cancer patients. CancerCare also offers limited financial assistance for treatment-related costs in New York City, Long Island, New Jersey, and Connecticut.

The Leukemia & Lymphoma Society (http://lls.org/hm_lls) has a Co-Pay Assistance Program that helps patients afford private health insurance premiums, private insurance co-pay obligations, Medicare Part B, Medicare Plan D, Medicare Supplementary Health Insurance, and Medicare Advantage premium or co-pay obligations.

The National Association of Community Health Centers (301-347-0400, www.nachc.com) lists local nonprofit, community-owned health care programs serving low-income and medically underserved urban and rural communities.

NeedyMeds (www.needymeds.com) is a clearinghouse for information about pharmaceutical manufacturers' assistance programs.

Oncolink (www.oncolink.upenn.edu), a widely respected Web site for cancer-related information, includes a special section, "Financial Issues for Patients."

The Patient Advocate Foundation (800-532-5274, www.patientadvocate.org) provides education and legal counseling for cancer patients about managed care, insurance, and financial issues.

The Partnership for Prescription Assistance (888-477-2669, www.pparx.org/Intro.php) lists pharmaceutical company programs that provide drugs to patients who could not otherwise afford them.

Public Sources of Information and Financial Assistance

Some hospitals and other health facilities that receive federal funding under a program called "Hill-Burton" (800-638-0742, www.hrsa.gov/hillburton/default.htm) must provide free or reduced-cost care for people who cannot pay for it.

The National Cancer Institute's Cancer Information Services (800-422-6237, www.nci.nih.gov) offers an extensive listing of financial assistance for cancer care.

The Social Security Administration (800-772-1213, www.ssa.gov) oversees several programs for providing financial assistance to qualified individuals. These programs include

disability insurance benefits, unemployment compensation, and supplemental security income for the disabled. (To determine whether your cancer is a disability under the law, the Social Security Administration considers what type of cancer you have, the extent of metastasis, and how you are responding to treatment.)

The Department of Veterans Affairs

(800-827-1000, www.va.gov) offers a variety of benefits to veterans. Although most disability benefits apply to veterans whose disability is service connected (which cancer seldom is), some benefits are available to cancer-survivor veterans. Hospital care in VA facilities is provided to veterans who meet certain standards—such as those who are eligible for Medicaid, need care related to exposure to cancer-causing substances, have a VA pension, or have a limited income. Outpatient care and medical equipment also are available under certain circumstances.

Deducting Medical Expenses from Your Taxes

Finally, part of the money you spend on medical care for yourself, your spouse, and your dependents may qualify as itemized deductions for federal income tax purposes. This would lower your tax bill. Keep track of what you pay for physician fees, prescription drugs, dental expenses, home nursing fees, hospital bills, medical insurance premiums that you (not your employer) paid, laboratory bills, and transportation and lodging if you sought medical care away from your local area.

Resources

NATIONAL COALITION FOR CANCER SURVIVORSHIP

“Financial Issues”

www.canceradvocacy.org/resources/financial.html

“Cancer Survival Toolbox”

www.canceradvocacy.org/toolbox

Visit the following section:

Finding Ways to Pay for Care.

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Live—and Live Well— Beyond Cancer

Surviving cancer is more complicated than simply being sick or healthy, having cancer or being cancer-free. Cancer survivorship is a day-to-day, ongoing process that begins with your diagnosis and continues through the rest of your life. *Living beyond cancer means striving to be as healthy as possible within your personal circumstances.*

Maintaining Your Health

Survivorship may extend for months, years, and even decades. Little is known about how to prevent the late effects of cancer, so it's extremely important that you monitor your health and develop a plan for life after cancer:

- Ask your doctor or nurse to help you develop a written treatment summary and monthly or yearly follow-up plan.
- Get the name of someone you can call if you become anxious or have questions.
- Ask for photocopies of your medical records, including surgery, pathology, and x-ray films and reports. Also gather details of all cancer treatments, such as the doses of chemotherapy drugs and the amount and location of radiation therapy.
- Keep track of your medical history so you will be able to supply a detailed account to any health care provider you see in the future.
- Go to a long-term follow-up clinic, sometimes called a “late effects” or “survivor” clinic, if one is available to you. (Cancer Survivors Project www.cancersurvivorsproject.org lists clinics across the country.)

Fostering Intimacy

Intimacy and fertility issues are often neglected topics for cancer survivors. During and after treatment, survivors may experience changes in their desire to be close to other people, in their levels of sexual desire and ability to enjoy sexual activity, and in their ability to have children. It is important to address these issues with your doctor and, possibly, with a mental health professional. Also, various fertility options can be explored through groups such as Fertile Hope at www.fertilehope.org.

Enriching Family Relationships

Researchers have found that some of the harshest realities that cancer survivors face are the reactions of the people closest to them. Open communication and mutual respect on the part of both survivor and family members are vital elements for creating a healing environment.

Dealing with Emotions

While many survivors will recover physically, they may have difficulty recovering from the emotional traumas that result from cancer and cancer treatment. Researchers have found that about one-third of cancer survivors experience anxiety or depression serious enough to require professional intervention. If you are experiencing emotional distress, you owe it to yourself to get help.

On the positive side, many survivors find themselves reevaluating their lives and shifting their priorities. They might experience a new zest and appreciation for life after moving past their painful experiences.

Getting Your House in Order

If it is important to you to “get your house in order”—to secure your future wishes through financial planning and by drafting a will and health care directives—consult a lawyer to work with you, and tell your family that you are making these plans.

There are two important legal documents that concern your future health care. A living will tells your doctors what medical care you want in case you’re unable to speak for yourself. A durable power of attorney for health care lets you name someone to make health care decisions for you if you become unable to do so.

Living with Hope, Dealing with Uncertainty

After being diagnosed with cancer, you may find yourself feeling insecure about your future. The good news is that studies show cancer survivors to be among the most resilient people when it comes to the ability to recover emotionally and regain optimism after trauma—and they can learn to be hopeful about the future.

The distinction between optimism and hopefulness is an important one for survivors. Optimism means emphasizing the positive aspects of a situation. Hope, on the other hand, is a way of feeling, a way of thinking, a way of behaving, and a way of relating to others. Hope is a necessary element for coping and healing.

Resources:

NATIONAL COALITION FOR CANCER SURVIVORSHIP

“Cancer Survival Toolbox”

www.canceradvocacy.org/toolbox

Visit the following section:

Living Beyond Cancer.

“Post-Treatment Guide”

www.canceradvocacy.org/resources/treatment-issues/post-treatment.html

“You Have the Right to Be Hopeful”

www.canceradvocacy.org/resources/publications/hopeful.pdf

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Care for Caregivers

One out of three people in the United States is diagnosed with cancer in their lifetime, so almost anyone can find him or herself providing care for someone—a parent, a child, a spouse, a partner, or a friend. Of all the challenges cancer brings you as a caregiver, two of the most substantial are facing the demands put on you and sorting out your feelings about what’s going on in your life.

Some days, you may feel overwhelmed, hopeless, resentful, or even angry. You can’t possibly be the superhero you seem expected to be. But on other days, you’re ready to fight for the survivor in your life; you see that you’re making progress; you remember that there’s always reason for hope.

The key is to recognize how natural all these thoughts and feelings are, including the one feeling you do not have to fear: the sense that you are failing. You’ve got the toughest job in the world—anything positive you can do is a victory.

Skills to Help You as a Caregiver

Learning how to balance the needs of the person you are caring for with your own needs takes time. To reach that goal, you’ll benefit by strengthening these basic skills:

- *Communicating.* Expressing your own needs and feelings, and being able to listen to the needs and feelings of others, is an important skill for everyone dealing with cancer. Yet many studies confirm what people often say: Communication can be difficult for cancer

survivors and their caregivers. Those who care about each other may not want to share the strong feelings that come with a diagnosis of cancer. When feelings about cancer are expressed, it gives people an opportunity to support each other, and reduce stress associated with anger or sadness. Communication does not make problems go away, but it can help you get support and understanding so you can manage cancer and its treatments more effectively.

- *Finding information.* As a caregiver for someone with cancer, you always need information—for making decisions, solving problems, and getting help. Searching for the information you need will help you better understand the disease and treatment, as well as locate resources and support.
- *Making decisions.* A diagnosis of cancer requires important decisions about treatment options and life choices. When the survivor is facing such decisions, it may be helpful for caregivers to offer assistance and perspective.

- ***Solving problems.*** You must be able to adapt to the changes brought about by cancer, and realize that you may need to accept outside help. Some places to look for assistance include your oncology nurse or social worker (if available), cancer organizations, advocacy groups, support groups of other cancer survivors, the Internet, friends, and of course, your own family.
- ***Negotiating.*** Reaching agreements that work best for everyone will make the caregiver role less stressful.
- ***Standing up for yourself and your loved one.*** Never hesitate to ask for what you need, whether it is for the cancer survivor you are caring for, or for yourself.
- Ask extended family and friends for help with activities like picking up prescriptions, grocery shopping, or taking your loved one to a doctor appointment.
- Don't cut yourself off from people and groups who can support you. For example, if you have always gone to religious services on a regular basis, continue to do so.
- Don't put your own life on hold. Keep appointments for medical and dental checkups. Eat a healthy diet, exercise, and get as much rest as you can.
- Don't feel you have to do everything yourself. While you may want and need to be the main caregiver, keep in mind that others can help, too.
- Find a strong support network. Talk to people with similar experiences or those in similar situations. It's essential to realize you are not alone.

Taking Care of Yourself

While you are building skills that will help you in the caregiver role, you also must remember your own needs, and develop the habit of taking care of yourself.

- Keep to your usual activities and routines as much as possible. This includes your work, hobbies, and exercise program, and spending time with friends.
- Take routine breaks from dwelling with the cancer crisis. Vacations, even if only for a day, can help refresh you.
- Don't assume that other people know what you think, feel, or need. Ask directly for what you need.

There's no question—being a caregiver is a hard job. There are times when you will feel burdened and exhausted. The most effective things you can do are take care of yourself and reach out to others. Don't let yourself become isolated from those who can help.

Resources

NATIONAL COALITION FOR CANCER SURVIVORSHIP

"Cancer Survival Toolbox"

www.canceradvocacy.org/toolbox

Visit the following section: *Caring for the Caregiver.*

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The Power of Advocacy

In cancer survivorship, advocacy is a continuum. It may begin at the personal level, but it may broaden to encompass group or organization advocacy—and later, public advocacy efforts.

Personal Advocacy

At diagnosis and during intensive cancer treatment, self-advocacy is a way of taking charge in an otherwise intimidating environment of diagnostic tests, surgery, radiation, chemotherapy, and doctors' offices. From supporting yourself with information about your diagnosis, to seeking second opinions, to locating resources for identifying and obtaining support, to knowing how to ask the right questions—your personal empowerment can mean the difference between maintaining a positive future outlook and feeling helpless.

The one to five years after a cancer diagnosis is a time of reentry and reevaluation of your life. It is during this time that cancer survivors realize that their lives will never be the same, and many survivors seek out other survivors with whom they can identify.

This life transformation calls for another type of self-advocacy. With the underlying idea that they “want to give something back,” in gratitude for their survival, many survivors seek out avenues to share their experience with others. This sharing of knowledge—the veteran helping the rookie—is what the survivorship movement is largely about. When

occurring in the context of a self-help group or within a professionally facilitated support group, this passing of wisdom from a more seasoned survivor to a newcomer provides a strong foundation for people who have had cancer to play a more active role in making decisions that will follow them the rest of their lives.

Advocacy for Others

Having been successful in exchanging information with others who share a cancer experience, survivors can extend their advocacy efforts to the larger community. Through networking with other persons in their area, survivors can learn more about specific issues. Supported once again with valuable information, cancer survivors can go on to tell others their shared experiences and advocate for changes that can have a broad impact on survivorship.

One of the easiest and most satisfying ways to advocate for others is to speak at the local community level—to church and civic groups, to medical students and physicians, oncology nurses, social workers, and others—to educate them about the complex interpersonal and

psychosocial issues that dominate survivors' lives. This public speaking becomes a testimony that affirms one's survival, defies many of the myths and stigmas about cancer, and perhaps reaches others who are silently struggling with similar issues.

Public Interest Advocacy

The exponential growth of the survivorship movement increasingly is realized by the many long-term survivors who go on to become professional survivor advocates. These individuals have taken their learned experiences from diagnosis, through treatment and recovery, and become advocates participating in the national cancer survivorship movement. Particularly notable among them are those who have effected change in public policy, including appropriations for cancer research; those who have pressed for more survivorship research; those who have given public witness testimony at both the local and federal levels of government; and those

who have contributed to the body of knowledge about living a better quality of life after a diagnosis of cancer, either through professional journals or the popular press. By telling "one's story," including through print and broadcast media, the net is cast much wider.

As people with a history of cancer recount their stories in the community and to the media, they become recognized experts on the compelling issues that have impacted their lives and the lives of the community of survivors with whom they have become involved. Depending on one's vocation, avocation, or other life circumstances, the interest one takes in sharing this experience is limited only by the desire to speak up—whether it is survivor to survivor in support groups, in the workplace, before state legislators, or to Congress. Advocacy is an invaluable skill set that can empower people with cancer and can maximize the quality of their own survival as well as that of others.

Excerpted from "Advocacy: The Cornerstone of Cancer Survivorship," by NCCS President & CEO Ellen Stovall & Elizabeth Johns Clark, PhD

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