

DISABILITY

INTRODUCTION

One of the major issues facing many cancer patients—and family members that may be caring for a person afflicted with cancer—is the disability that may result from the disease itself or the effects of various cancer treatments, or both. Disability can affect cancer patients in two critical areas: (1) employment and (2) the inability to make important decisions about health care, finances and other personal matters. An individual’s employment typically provides not only income, but critical benefits such as health insurance. Multiple issues, such as workplace discrimination and financial strain, may arise when cancer or cancer treatment affects a patient’s ability to work.

With respect to the inability to make important decisions, you should consider having certain legal documents, such as a medical power of attorney and a directive to physicians, prepared in the event that your illness or the treatment of your illness renders you unable to make medical decisions for yourself. Both of these key issues are discussed in detail in the: (1) Employment Law and (2) Estate Planning sections of this Guide, so they will not be the primary focus of this section on disability, but you should be aware of the overlapping nature of these topics and consult the Employment and Estate Planning sections for a more in-depth and informative analysis of these issues. The focus of this section is on resources to help you deal with disability that may result from cancer or its treatment.

At the outset, it is important to note that the definition of “disability” itself will likely vary, depending on whether a particular statute (such as the Americans with Disabilities Act) applies, or may even be referred to in a different way. For example, the Family and Medical Leave Act defines disability as a “serious health condition.” Various non-profit organizations that assist cancer patients may have also different guidelines. Thus, it is generally a good idea to consult with the public or private resources for guidance.

DISABILITY AND EMPLOYMENT

What can I do if my illness or the treatments for my illness impact my ability to work?

Cancer, cancer treatment, or the lingering effects of both following the end of treatment may affect a cancer survivor’s ability to do his or her job. Most employers treat cancer survivors fairly and legally, but sometimes employers discriminate against cancer survivors based upon: (1) unfair assumptions about what people who have survived cancer can or cannot do in the workplace; (2) fears about rising insurance

costs; (3) the time requirements needed for treatment and doctors' appointments; (4) the need to travel for treatment; and (5) numerous other issues associated with cancer and its effects upon a person. As a result, some survivors have encountered problems such as dismissal, failure to be hired, demotion, denial of promotion, denial of benefits, and undesirable transfers. The Americans with Disabilities Act (ADA) may protect you from certain discriminatory practices, and may require your employer to provide you with "reasonable accommodations" such as alternative work hours or changed job duties to allow you to perform the essential functions of your job. It may also protect individuals who have a relationship with someone who has been disabled by cancer or cancer treatment. Other legislation, such as the Family Medical and Leave Act (FMLA), which permits a person to take up to twelve weeks of unpaid leave in a year for, among other things, a serious health condition or to care for a seriously ill spouse, parent or child, may also assist those who are diagnosed with cancer and their loved ones. The FMLA protects the employee's job during that time period.

This is a very brief summary of disability as it relates to employment, and is really intended only to make you aware that there are laws in place to protect you or your family member(s) in the event cancer makes it difficult to continue working. For a more detailed discussion, please consult the Employment Law section of this Guide.

INCAPACITY

How do I take care of myself in the event my health affects my ability to make decisions?

At some point in your life, whether it is from this fight with cancer or some other illness in the future, you may become unable to make decisions about your health care or other important matters, such as your finances, due to the effects of the illness or due to the treatment of the illness. In the event of such incapacity, you should have several legal documents in place that either (1) delegate such decisions to a trusted friend or family member, and/or (2) make your wishes about such critical issues known to your caregivers. These documents, which are discussed in detail in the Estate Planning and End of Life sections of this Guide, include a power of attorney, a medical power of attorney, a will, and a directive to physicians. Please consult the Estate Planning and End of Life sections for more information and guidance regarding these matters.

FINANCIAL ISSUES ASSOCIATED WITH DISABILITY

What are some private resources for financial assistance and information?⁽¹⁴⁾

There are many organizations that provide financial assistance for the costs

(14) Many of the resources are also excellent sources of information for a multitude of issues not related to finances.

associated with medical care. There are a number of programs offered by a variety of organizations, and each program may vary widely by location and organization. For example, there are organizations that have volunteer programs to help provide cancer patients with transportation to and from treatment, organizations that have “lending libraries” of wigs, hospital beds, wheelchairs and related products, and organizations that offer financial assistance to patients having trouble paying their bills. It is important to note that organizations frequently do not publicize the assistance and available services they may offer, so do not hesitate to inquire about any programs offered by a particular organization. Also, remember to investigate any local charities or non-profit organizations for additional assistance programs—there are numerous regional non-profit organizations that provide excellent financial assistance.

Resources to contact for financial assistance include⁽¹⁵⁾:

Cancer Care

275 Seventh Avenue
New York, NY 10001
1-800-813-HOPE (1-800-813-4673)
<http://www.cancercares.org>

CancerCare is a national nonprofit agency that offers free support, information, financial assistance, and practical help to people with cancer and their loved ones. Financial assistance is given in the form of limited grants for certain treatment expenses. Services are provided by oncology social workers and are available in person, over the telephone, and through the agency’s Web site. CancerCare’s reach also extends to professionals—providing education, information, and assistance. A section of the CancerCare Web site and some publications are available in Spanish, and staff can respond to calls and e-mails in Spanish. Information about financial assistance for all cancers is available at http://www.cancercares.org/get_help/assistance/cc_financial.php.

CancerCare has also partnered with the Susan G. Komen Breast Cancer Foundation to create the Linking A.R.M.S. program, which provides limited financial assistance for hormonal and oral chemotherapy, pain and antinausea medication, lymphedema supplies, and durable medical equipment for women with breast cancer.

(15) Many of these resources are listed on the website maintained by the National Coalition for Cancer Survivorship at www.canceradvocacy.org, and the National Cancer Institute at www.cancer.gov, and various other websites dealing with cancer.

Leukemia and Lymphoma Society (LLS)

1311 Mamaroneck Ave.
White Plains, NY 10605
(800) 955-4572
<http://www.leukemia-lymphoma.org>

The Leukemia and Lymphoma Society (LLS) offers information and financial aid to patients in significant financial need who have leukemia, non-Hodgkin's lymphoma, Hodgkin's lymphoma, or multiple myeloma. The LLS's "Patient Financial Aid" Web page provides more information about the types of service available, application forms, and eligibility requirements at http://www.leukemia-lymphoma.org/all_page?item_id=4603.

Lance Armstrong Foundation

P.O. Box 161150
Austin, TX 78716-1150
(512) 236-8820 and (866) 235-7205
<http://www.livestrong.org>

LIVESTRONG™ SurvivorCare offers counseling services, help with financial, employment or insurance issues and information about treatment options and new treatments in development. LIVESTRONG™ SurvivorCare is a program of the Lance Armstrong Foundation, in partnership with CancerCare, Patient Advocate Foundation and EmergingMed. To speak to a case manager, call LIVESTRONG™ SurvivorCare toll-free at 866.235.7205 or visit www.livestrong.org

National Association of Community Health Centers, Inc.

1330 New Hampshire Avenue, NW, Suite 122
Washington, DC 20036
(202) 659-8008
www.nachc.com

The National Association of Community Health Centers provides a listing of local nonprofit, community-owned health care programs serving low income and medically under-served urban and rural communities.

Needy Meds

www.needymeds.com

Needy Meds is a resource for free information about getting medications from pharmaceutical companies.

Oncolink

Abramson Cancer Center of Pennsylvania

3400 Spruce Street – 2 Donner

Philadelphia, PA 19104-4283

oncolink.upenn.edu

Oncolink, managed by the University of Pennsylvania, is a website for cancer-related information that includes a special section, Financial Issues for Patients, which provides information on reimbursement assistance programs.

Partnership for Prescription Assistance

(888) 4PPA-NOW (1-888-477-2669)

www.pparx.org

The Partnership for Prescription Assistance (PPA) brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that is right for them. Many will get them free or nearly free. Through this site, PPA offers a single point of access to more than 475 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies.

Patient Advocate Foundation

780 Pilot House Drive, Suite 100-C

Newport News, VA 23606

(800) 532-5274

www.patientadvocate.org

The Patient Advocate Foundation provides education and legal counseling about managed care, insurance, and financial issues for cancer patients.

Road to Recovery

(800) ACS-2345

www.cancer.org

The Road to Recovery is an ACS service program that provides transportation for cancer patients to their treatments and home again. Transportation is provided according to the needs and available resources in the community and can be arranged by calling the toll-free number or by contacting the local ACS office.

Ronald McDonald Houses/Charities

One Kroc Drive

Oak Brook, IL 60523

(630) 623-7048

<http://www.rmhc.com>

Ronald McDonald Houses provide a “home away from home” for families of seriously ill children receiving treatment at nearby hospitals. Ronald McDonald Houses are temporary residences near the medical facility, where family members can sleep, eat, relax, and find support from other families in similar situations. In return, families are asked to make a donation ranging on average from \$5 to \$20 per day, but if that isn't possible, their stay is free. To search for a Ronald McDonald House location, go to http://www.rmhc.com/rmhc/index/search_house.html.

Taking Charge of Money Matters

(800) ACS-2345

www.cancer.org

The American Cancer Society offers Taking Charge of Money Matters, a workshop for people with cancer and their loved ones about financial concerns that may arise during or after cancer treatment, regardless of the person's health insurance coverage. The session provides an opportunity to discuss financial matters with guest speakers who are knowledgeable about financial planning. More information about this workshop is available on the ACS Web page at http://www.cancer.org/docroot/SHR/content/SHR_2.1_x_Taking_Charge_of_Money_Matters.asp?sitearea=SHR.

Tender Loving Care®

(800) ACS-2345

www.cancer.org

The American Cancer Society's "tlc" **Tender Loving Care**® publication contains helpful articles and information, including products for women coping with cancer or any cancer treatment that causes hair loss. Products include wigs, hairpieces, breast forms, prostheses, bras, hats, turbans, swimwear, and helpful accessories at the lowest possible prices. The publication strives to help women facing cancer treatment cope with the appearance-related side effects of cancer. To request a copy of "tlc," call 1-(800)-850-9445, or visit "tlc" at <http://www.tlccatalog.org>.

What are some governmental resources for financial assistance?

Medical Assistance Programs

The Breast and Cervical Cancer Treatment Act provides, in most states, Medicaid coverage for treatment to women who have been screened for and diagnosed with breast or cervical cancer, including precancerous conditions, through the National Breast and Cervical Cancer Early Detection Program. For more information about eligibility and contacts for this program, visit the Centers for Disease Control and Prevention's (CDC) "Breast and Cervical Cancer Prevention and Treatment Act of 2000" Web page, which is located at <http://www.cdc.gov/CAN-CER/nbccedp/law106-354.htm>.

COBRA is a federal act allowing individuals who lose employer health insurance coverage to buy group insurance for themselves and their families for limited periods of time. This may be helpful to consider if you have a waiting period to get through before Medicare or Medicaid take effect. To apply, contact your employer or group health insurance plan.

Hill-Burton

(800) 638-0742 (Maryland residents call 1-800-492-0359).
<http://www.hrsa.gov/hillburton/default.htm>.

Hill-Burton is a program through which hospitals receive construction and modernization funds from the Federal Government. Hospitals that receive Hill-Burton funds are required by law to provide a reasonable volume of services to people who cannot afford to pay for their hospitalization and make their services available to all residents in the facility's area. Information about Hill-Burton facilities is available by calling the toll-free number or visiting the Web site listed above. A brochure about the program is available in Spanish.

Medicare is a federal health insurance for those 65 or older or those who have been receiving Social Security Disability benefits for a full two years, regardless of age. For more information on Medicare, contact the Medicare Rights Center at (212) 869-3850.

Medicaid is a joint federal and state run program that provides health insurance to people meeting income and asset restriction guidelines. Apply through your local Social Service/Public Welfare Department. Additional information can be found at www.cms.hhs.gov/home/medicaid.asp. The telephone number is 1-800-252-8263.

State Children’s Health Insurance Program (SCHIP)

(877) 543-7669 (1-877-KIDS-NOW)

<http://www.insurekidsnow.gov>

The State Children’s Health Insurance Program (SCHIP) is a Federal-State partnership that offers low-cost or free health insurance coverage to uninsured infants, children, and teens. Callers will be referred to the program in their state for further information about what the program covers, who is eligible, and the minimum qualifications. In most states, uninsured children age 18 and younger whose families earn up to \$34,100 a year (for a family of 4) are eligible. For a list of health insurance coverage and eligibility by state, go to <http://www.insurekidsnow.gov/states.htm>.

Senior Prescription plans are offered by many states that provide affordable access to medications for seniors. Contact your department of aging or local legal aid program for information.

In-Kind Help

Food stamps can provide financial help for buying food. If you are having problems paying for food, it is a good idea to apply for food stamps even if you’re not sure you qualify because you may just be approved.

Home Energy Assistance Program (HEAP) and Weatherization Assistance Program help low-income homeowners and renters pay for fuel and utility expenses, or help weatherize their homes.

There are a variety of state programs to help people subsidize housing costs, reduce property tax costs, provide exemption from rent increases, and make available emergency cash for crisis situations. Ask your local Social Service Department or hospital social worker about your state’s programs.

Income Replacement Programs

NCI’s Cancer Information Services

(800) 4-CANCER (1-800-422-6237)

www.cancer.gov

The National Cancer Institute's Cancer Information Services offers an extensive listing of financial assistance for cancer care. Some, but not all, of the resources are listed here.

Social Security Benefits

There are several programs under the Social Security Act that provide financial assistance to individuals who qualify. These programs include disability insurance benefits, unemployment compensation, and supplemental security income for the disabled, and are discussed in more detail below. For more information about these programs, contact the Social Security Administration's toll-free hotline at (800) 772-1213.

Retirement Benefits Under Social Security

To be eligible for retirement benefits, you need not be disabled or in financial difficulty. The only requirement is that you be of a certain age and have paid into the Social Security system.

Under certain circumstances, spouses or other related persons may receive additional benefits. For example, a widow, widower, surviving divorced spouse, child or parent of a person who was entitled to Social Security benefits may directly receive benefits if certain conditions are met.

The **Supplemental Security Income (SSI) Benefits** program is designed to provide income to people 65 or over whose income is below the federal minimum level, and who are blind or disabled. Eligibility is determined by need, not whether you have paid into Social Security when you worked. Although SSI payments can be quite small, in many states an individual receiving SSI benefits will automatically be eligible for Medicaid and also may receive a state supplemental payment. <http://www.ssa.gov/notices/supplemental-security-income>

Disability Insurance Benefits Under Social Security

Disability benefits are designed to provide income to people who are unable to work because of a disability. You are entitled to receive disability benefits while you are disabled before the age of 65 if:

- You have enough Social Security earnings to be insured for disability;
- You apply for benefits;
- You have a physical or mental disability that prevents you from doing any substantial gainful work;

- The disability must be expected to last, or has lasted, at least 12 months, or must be expected to result in death; and
- You have been disabled for five consecutive months.

In some cases, spouses of disabled claimants also are entitled to benefits.

The amount of disability benefits is based on a sliding scale percentage of wages determined by elaborate, frequently changing formulas based on your age and past earnings. An employed person may not collect benefits. Workers may not receive both workers' compensation and Social Security disability for the same illness. The medical records of individuals who apply for Social Security disability are evaluated according to regulations issued by the Social Security Administration. Individuals who are denied benefits may appeal to an administrative law judge.

To determine whether your cancer is a disability under the law, the Social Security Administration considers: (1) what type of cancer you have; (2) whether it has spread; and (3) how you are responding to treatment.⁽¹⁶⁾ Small tumors that have not spread and that respond to therapy usually do not constitute an impairment. For example, early stage breast cancer that is successfully treated with surgery is not considered a severe impairment. Cancer that has spread beyond regional lymph nodes, however, is usually considered a severe impairment. Otherwise, your diagnosis is evaluated on a case-by-case basis.

Veteran's Benefits

The Department of Veterans Affairs (DVA) offers a variety of benefits to veterans. Although most disability benefits apply to veterans whose disability is related to their military service, some benefits are available to cancer survivor veterans.

Depending on when you served, your age, and your income, you may be eligible for a nonservice connected pension. An additional allowance may be paid if you are in a nursing home, need a home aid, or are housebound because of your illness.

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 (such as Dioxin, Agent Orange, or nuclear fallout), have a VA pension, or have a limited income. Outpatient care and medical equipment also are available under certain circumstances.

(16) The definition of "disability" used by the Social Security Administration differs from the ADA definition of disability. For the ADA definition of disability, please refer to the Employment Law section.

Additionally, the DVA offers a variety of other benefits to qualified veterans, including life insurance, burial benefits, death pension to your dependents if your death is nonservice connected, and civil service preference certificates if you seek government employment. For more information, contact:

Department of Veterans Affairs

www.va.gov

Department of Federal Benefits for Veterans and Dependents

(800) 827-1000

The Uniform Benefits Package Enrollment Service Center

(877) 222-VETS (8387)

DEDUCTING MEDICAL EXPENSES FROM YOUR TAXES

Part of the money you spend on medical care for yourself, your spouse, and your dependents may be itemized deductions for federal income tax purposes. Consequently, you should keep track of your physician fees, prescription drug expenses, 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 home.

At the end of the calendar year, add up all of your medical expenses. From this number, you must then subtract a percentage of your gross income. You may deduct the balance from your income subject to federal income tax.

The Internal Revenue Service (IRS) has a number of free publications that describe potential deductions related to health care. An IRS counselor will also answer over the telephone your questions about the tax regulations.

Internal Revenue Service

(800) 829 1040 for information

(800) 829-3676 for publications