



SELF-ADVOCACY

A Cancer Survivor's Handbook

A publication of the



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

Legal Disclaimer

This publication has been created by the National Coalition for Cancer Survivorship (NCCS) to provide general information about cancer advocacy and to serve as a resource for people experiencing a diagnosis of cancer. This resource represents the opinions of NCCS and is not designed to provide individual advice nor to substitute for professional counsel.

Second Edition

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Dedicated with appreciation to the founders of the National Coalition for Cancer Survivorship (NCCS). In 1986, it was your conviction that one day there would be a nationwide awareness of cancer survivorship, and that all those diagnosed with cancer would view themselves as “survivors,” rather than “victims.” This publication salutes your vision, your dedication and your desire to assure that all people diagnosed with cancer will know, first and foremost, how to become advocates for themselves.

ACKNOWLEDGEMENTS

The content of this handbook represents the collective wisdom about *self-advocacy* derived from the published articles, books and other writings of many leaders of NCCS over more than 20 years. Many of these include NCCS founding members, board members and cancer survivors, Fitzhugh Mullan, MD; Catherine Logan; Susan Leigh, RN; Barbara Hoffman, JD; Barbara Carter, PhD; Natalie Davis Spingarn; Larry Moore; Dean Gesme, MD; Elizabeth Clark, PhD; and Ellen Stovall.

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PREFACE

If you have picked up this handbook, it is likely that cancer has become an unwelcome intruder in your life. With notable exceptions, few common medical conditions create as much fear, stigma and anxiety as cancer. The National Coalition for Cancer Survivorship (NCCS) believes that cancer becomes a much lesser foe when faced by an individual who is informed and knowledgeable and who knows how to communicate their needs to those who can be helpful to them as they experience cancer. This handbook is intended to help you become such an individual – a cancer advocate – to lessen the fear, dispel the myths, and reduce the anxiety, so that you can make the best decisions about your survivorship.

The majority of individuals on the Board of Directors and staff of NCCS have had a personal diagnosis of cancer. They have learned that, while each one of us experiences cancer as an individual, there is some collective wisdom to be derived from what they have learned as a community of advocates for people who are living and dying well with cancer. They pass their learning on to you through this handbook. You will find additional resources and publications at the back of this handbook.

This handbook is not a comprehensive guide. Moreover, cancer comprises more than 100 diseases, and the conditions under which we experience cancer (our home, family, friends, finances, spiritual beliefs, employment, community) influence how we adjust to cancer as a life-changing experience. This handbook is, however, a primer intended to encourage and enable you to become an active participant as you deal with a diagnosis of cancer, no matter what your life circumstances. Many phrases and expressions found in this handbook are repeated throughout. This is intentional, to reinforce the importance and purpose of the term *self-advocacy*.

This handbook focuses on self-training steps and tools to assist and empower individuals dealing with cancer. If you are at the beginning, middle, or end of your decision-making about dealing with a diagnosis of cancer, the materials in this handbook will add value to your survivorship.

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Sending a patient to do battle with cancer without any training is like parachuting a soldier into the jungle without the benefit of survival training.

*Michael Lerner, PhD, President & Founder, Commonwealth
Founding Member, National Coalition for Cancer Survivorship*

HOW TO USE THIS HANDBOOK

This handbook is designed to assist you at many points in your cancer experience. You can use it upon diagnosis or refer to it many years later. Select the topic areas that relate to your situation and refer to this handbook at any time and in any order you choose. Share it with a friend, colleague, family member or health professional to broaden the circle of advocates who can be helpful with your diagnosis of cancer.

GETTING STARTED

Some would say that, ideally, upon a diagnosis of cancer or other life-threatening illness, a person would be provided a patient advocate. Unfortunately our society is far from using this model. Therefore, NCCS has developed materials, programs and skill-building tools to enable individuals and their supporters to become effective self-advocates. You can think of these as your advocacy tools as you begin your journey of survivorship.

The materials and tools in this handbook are based on the experiences of many survivors and are intended to help you “become your own best advocate.” Cancer survivorship as defined by NCCS is an ongoing process – one that begins at diagnosis and continues for the balance of your life.

To paraphrase the Taoist philosopher Lao-Tzu, every journey begins with a single step. No matter where you are in your cancer journey, the step you take now may be *your* first to become more informed and feel more empowered to adjust to this diagnosis. Ideally, you are dealing with cancer with the support of many friends, loved ones and compassionate caregivers. Too often, people experience cancer in isolation, without financial or emotional support and with few resources to tap into. No matter what your circumstances, always keep in mind that you can always do something – even if that something just gets you through the next hour or the day. And remember, no matter where you are along the path of your survivorship, having good skills to negotiate and communicate your needs are some of your best weapons to use against cancer.

DEFINING TERMS

Three words appear often throughout this handbook: **survivor**, **survivorship** and **advocacy**.

The NCCS Charter reads as follows:

*From the moment of diagnosis and for the balance of life, an individual diagnosed with cancer is a **survivor**.*

In 1986, the founders of NCCS put the term **survivor** into our dictionary of terms to replace “patient” or “victim” to describe someone diagnosed with cancer. The word **survivor** is often debated, but NCCS persists in using it because of the proactive approach it emphasizes when living with a diagnosis of cancer. The founders of NCCS also extended the term **survivor** to apply to an individual’s friends and caregivers.

The term **survivorship**, as defined by the founders of NCCS, *is the experience of living with, through and beyond a diagnosis of cancer.* NCCS includes the process of dying well as the last stage of survivorship. It is NCCS’s belief that by living and dying well with cancer, an individual and all those who care for him/her, will pass on a legacy of survivorship to all those they come in contact with.

The term **advocacy** is frequently used to encompass activities carried out in the name of supporting a cause. The dictionary defines **advocacy** as “active support, as of a cause, idea or policy.”

Advocacy, as NCCS defines it, is a continuum that begins when an individual is diagnosed with cancer. NCCS believes that at this defining moment, an individual with cancer (and/or a significant person in his or her life) must play a very active role in assuring that they receive quality care. This marks the first step in the cancer advocacy continuum. The next step in the continuum is what NCCS defines as “advocacy for others.” This is where some of the most effective advocacy occurs for individuals with cancer and it is where many people with cancer find a role for themselves as advocates in their own community. At the other end of the continuum is advocacy in the public interest, or national health care advocacy, and this is the chief role of organizations like NCCS.

This handbook touches on all three areas, but focuses principally on **self-advocacy**, and explains how you can become the most effective advocate when you or someone you care about has cancer.

BECOMING A SELF-ADVOCATE

What Is Self-Advocacy and How Does It Apply To Me?

Self-advocacy does *not* mean that you have to wave a banner, give speeches or take to the ramparts. In the personal context, it means that you arm yourself with the tools and skills necessary to feel comfortable about asserting yourself and communicating clearly about your cancer care needs. It ultimately means that you are taking responsibility and assuming some control of your life circumstances with cancer.

Dr. Patricia Ganz, a founding member of NCCS and a respected oncologist, wrote: Knowing as much as possible about your disease, its treatments and its potential effects on your body can empower you to take charge of your health and help you make the most of your survivorship experience.

It is *imperative* that survivors, their health care providers and other supporters become effective advocates in the current environment of rising health care costs and restrictive referral policies. Health care professionals are also experiencing ongoing pressures such as nursing shortages and restrictive reimbursement policies for health care services. These all have an adverse impact on the care we receive and the system in which it is provided. Our interdependency on one another for responsible advocacy can strengthen the health care environment in which we are treated for cancer.

Why is Self-Advocacy Important?

By being a proactive, educated cancer consumer/advocate, you can impact the quality of your life and the health care you receive. Ellen Stovall, cancer survivor and NCCS President and CEO and Elizabeth Johns Clark, PhD, MSW, have identified and written about some of the important reasons for self-advocacy.

- Advocacy gives you some stability and a feeling of regaining some control in your life.
- Advocacy is confidence building in the way it helps you face challenges that seem insurmountable.
- Advocacy is a way of reaching out to others. It can be as simple as asking your doctor or nurse for the name of someone to talk with who has survived your particular type of cancer.
- Advocacy can improve your quality of life.
- Advocacy for yourself may be the difference that turns feeling hopeless and helpless into feeling hopeful.

Stated in another way, self-advocacy is a synonym for what some might otherwise call “control” or “empowerment.” Self-advocacy implies strength, both physical and mental. Self-advocacy requires participation in the decision-making process. Given our tremendous access to resources for information and support today, a self-advocate need not go to a medical provider and say, “What would you do,” or “I’m in your hands” or “just cure me.” Commitment to shared responsibility with your medical team can contribute to the goal of physical, emotional, and mental health.

Who Are Cancer Advocates?

We are *all* cancer advocates – ourselves, our families, friends, health care professionals, and caregivers. It is anyone taking the necessary steps to play an active role as an informed, communicative decision-maker about treatment and quality-of-life after a cancer diagnosis. It is anyone reading and using the suggestions in this handbook. It is anyone empowered by NCCS's *Cancer Survivors' Bill of Rights*. It is anyone advocating on behalf of themselves, or others, at the personal, community, state or national level. We are part of a growing constituency of people living with, through and beyond cancer.

What Role Does NCCS Play in Empowering Survivors and Promoting Self-Advocacy?

Many excellent cancer organizations play a role in advocating for individuals with cancer. Many of them also fund research, provide professional and patient education, and/or offer support services. These organizations are principally governed by physicians and professional caregivers and have a very important voice in the cancer community. NCCS prides itself on working with all of them.

The origins of NCCS are different and at the same time, similar to many of the patient advocacy organizations that provide information, support and advocacy on public issues for specific types of cancer, such as breast, prostate, ovarian, lung, colorectal, leukemia and lymphoma. Most organizations that deal with specific cancers were founded by individuals (and/or their caregivers) who were diagnosed with these specific types of cancer. NCCS is one of a handful of national cancer organizations founded by individuals with all types of cancer and their caregivers and health professionals. Because we don't focus on one type of cancer, our educational programs and publications provide general information that can apply to any type of cancer.

We develop all our programs, publications and policies from the perspective of cancer survivors and their advocates. This means that *we've been there*, having experienced cancer personally. We have learned to marry our personal experiences with cancer with the evidence that underlies good science and health policy. Next, we take the passion we feel as survivors into national forums that determine health care policy.

The Cancer Survivors' Bill of Rights

By knowing and standing up for your rights as a cancer survivor, you can affect your personal cancer experience in a positive way. An excerpted edition of The Cancer Survivors' Bill of Rights, written in 1988 and revised for NCCS in 1999 by the late Natalie Davis Spingarn, can be found at the back of this handbook. It is a document much like the Declaration of Independence that exemplifies the ideal and inspires us to achieve it.

OUR CONSTITUENCY

The National Cancer Institute (NCI) estimates that approximately 12 million cancer survivors in the United States were alive in 2008. These five-year survival figures have been steadily increasing due to heightened awareness, better screening techniques (which can lead to early detection) and new and advanced treatments for many types of cancer.

The Demographics of Cancer

As we examine the faces and voices of cancer survivorship, we see many disparities – disparities in age, ethnicity, literacy and socioeconomic status. Consider this compelling statistic: approximately 77% of all cancers are now diagnosed in people age 55 and older (NCI SEER Data, 2007). Too many of those diagnosed are culturally and economically underserved – both uninsured and underinsured. The 2000 Census figures indicate that there are 35 million Americans aged 65 or older, a 12% increase since 1990. It is projected that by 2030, one in five people will be age 65 or older. Our aging population is significant because cancer occurrence increases with age.

Childhood Cancer Survivors

At the other end of the scale, while childhood cancers are rare, the number of childhood cancer survivors is increasing and NCI reports that the number of childhood cancer survivors now exceeds 300,000. Susan Weiner, PhD, President of The Children’s Cause For Cancer Advocacy, an organization devoted to childhood cancer advocacy, states: “Research is revealing that young survivors, depending on their disease and its treatment, may be left with serious problems with reproduction, osteoporosis, heart functioning and second cancers.”

SELF-ADVOCACY SKILLS

Based on a review of survivorship research and writing, Elizabeth Clark and Ellen Stovall identified four primary, but interconnected areas, in which self-advocacy skills are essential: information-seeking, communication, problem-solving and negotiation. These skills can be self-taught and *The Cancer Survival Toolbox*[®], developed by NCCS and several professional organizations, provides self-help assistance on these and other topics, including “Standing Up For Your Rights.” See the Resource section at the end of this book for additional information. Although there are differences, these skills each serve to reinforce one another.

Information Seeking skills are developed by educating yourself as thoroughly as possible about your cancer, your treatment options, possible side effects and available support services. You have probably heard the tagline for a national retailer that states “an informed consumer is our best customer.” This is especially true when dealing with cancer.

Communication skills development is designed to help you organize your thoughts before you speak. Your communication skills can be applied to thoughtful interactions with your family, friends and caregivers, thereby increasing your knowledge and avoiding unnecessary misunderstandings. NCCS’ booklet *Teamwork: The Cancer Patient’s Guide to Talking With Your Doctor*, addresses many of the concerns and questions that you may have and provides a guide for effectively communicating them to others. Information about *Teamwork* is provided in Resources at the end of this handbook.

Problem-Solving skills can be also thought of as decision-making skills and are essential to the process of becoming an active, rather than passive, survivor. It is important to identify the problem and know how to articulate it – whether or not to have treatment and, if so, what type of treatment; considering a clinical trial; what physician to choose; and so on. Do not feel that you have to make decisions alone. The team approach often serves as the best way to tackle a problem.

Negotiation skills are necessary in every aspect of life, whether dealing with cancer or any other challenging life circumstances. Some of us are better at negotiation than others, but all of us can achieve some degree of skill in this area. Negotiating in order to get your needs met may require you to step out of your normal comfort zone. This does not mean that you become confrontational, but rather that you negotiate about issues that are of personal importance such as the accommodation of unconventional hours at your office or persuading your insurance company to cover a test or procedure.

BEING PROACTIVE: APPLYING THESE SKILLS

Now that you know why self-advocacy is important and how to acquire the necessary skills, you must actively apply them to your personal experience.

BEFORE DIAGNOSIS

What follows are some steps to reduce your misunderstanding and to increase the opportunity to get the best care, if and when you learn that you or someone you care about is diagnosed with cancer.

- ❑ **Study and understand your health insurance coverage.** It is important to fully understand your choice of facilities and health care providers when selecting a health plan. Those who advise you to seek second opinions, find another doctor, go to a major cancer center, etc., may believe that they are providing sound advice. However, you may face barriers to accessing this type of care based on your insurance coverage. If you think that you might want to get an opinion or treatment at a major cancer center and/or specialist out of your area (if you are diagnosed), make sure that you fully understand your “out of network” benefits. If you don’t, contact your health plan or your employer’s benefits administrator.
- ❑ **Headlines are meant to sell newspapers and magazines and can be misleading.** Hardly a day goes by without a news story heralding some breakthrough or major finding about cancer. One headline tells us certain foods may increase our risk for cancer, while another study and story may dispute that evidence. Our knowledge of cancer risks is constantly changing and may be more or less significant than current literature would suggest. Scientific knowledge about what puts us at risk for cancer evolves constantly. Keeping up with this kind of news helps you remain an “active” rather than a “passive” consumer. Never hesitate to raise questions with your health care professionals about your risk for cancer based on current evidence.
- ❑ **Engage in practices that reduce your risk of exposure to known cancer causing agents.** We all look forward to the day when we will know for certain what causes cancer. Two very difficult cancers are largely, though not always, caused by lifestyle choices – lung cancer and skin cancer. You can lessen your risk of developing these cancers by not smoking or using tobacco products and by limiting sun exposure. Guidelines regarding screening for the most common cancers are constantly evolving. Check with your physician to determine how the most current evidence regarding screening for breast, prostate, lung and colorectal cancer may apply to you.
- ❑ **History is not destiny.** If you have a family history of cancer, ask your physician what role genetics or other risk factors may apply to your particular health profile. Understanding “relative risk” versus “actual risk” marks an important distinction when dealing with genetic or heritable risk factors for cancer.
- ❑ **Know and trust your body and your instincts.** See your physician with any unusual symptoms that do not clear up in two weeks. If you are unsatisfied or instinctively sense that something is wrong, seek another opinion.

DIAGNOSIS

After persons receive a diagnosis of serious illness, the support they need varies as widely as humanity itself. Some want to have family gathered around them, others need to be alone. Some need assurance of immediate medical intervention, others have to have some time to decide what treatment they want. A physician may help one person by rushing in, another, by backing off. The caregiver's art is finding a way to allow the ill person to express his needs.

Arthur Frank, *At the Will of the Body*

The field of health care that deals with cancer is called *oncology*. The people treating cancer are chiefly medical oncologists, surgical oncologists, radiation oncologists, oncology nurses and oncology social workers.

Cancer is many diseases with one thing in common: the uncontrollable growth and accumulation of abnormal cells. Cancer growth and development has so many phases that physicians use terms that specify where the cancer is (site) and the type of tissue involved. Because there are so many different types of cancer, it is vitally important that you understand your diagnosis and prognosis – a prediction of the probable cause and outcome of the disease – so that you can make informed treatment decisions.

- ❑ **Become educated about your type of disease and the treatments available.** Rarely is there only one treatment option to consider. If you are emotionally or physically unable, ask a friend or family member to do the research for you. *Consider that a high quality clinical trial may be your very best treatment option. Be sure to ask your physician about this option.* (See page 12 for more information on clinical trials)
- ❑ **Be sure that you understand the stage and grade of your cancer.** For most cancers staging is based on a scale of 0-5 that identifies the size of the tumor and the extent of its spread. Grade compares the cancer cells characteristics to that of normal cells. These factors may determine treatment options.
- ❑ **Use credible and reputable sources of information** such as the National Cancer Institute; U.S. National Library of Medicine; American Cancer Society; American Society of Clinical Oncology; Cancer Care, Inc; or many of the site-specific cancer organizations. NCCS provides an interactive resource guide by subject at www.canceradvocacy.org. You can gain access to these resources by telephone, by fax, at your local library and/or on the Internet. A resource list is also included at the back of this handbook.
- ❑ **Write out your questions in advance of your visit to an oncology professional.** Some physicians will let you submit questions in advance of your first visit to allow for a more focused discussion.
- ❑ **Investigate living wills and advanced directives** so that your wishes are carried out throughout the entire course of your life.
- ❑ **Take steps to assure quality cancer care** (see the next section of this handbook).
- ❑ **Take some time to do the necessary research to make the choices that are best for you.** Don't let anyone pressure you into making an immediate decision about your treatment options.

ASSURING QUALITY CANCER CARE

“I was overwhelmed by all the information I was receiving and by the choices and decisions that I had to make, but I knew that my survival could depend on the knowledge and experience of the physician and the health care team that I chose.”

When diagnosed with cancer, you deserve the best possible care through your diagnosis, treatment, recovery and long-term follow-up. *Ensuring Quality Cancer Care*, a report of the Institute of Medicine and the National Research Council, found that a substantial proportion of cancer patients do not receive the best quality care. The report recommends systems changes to improve the likelihood that more people will receive high-quality cancer care in the future. NCCS is working very hard on a national advocacy agenda to assure that all Americans can access this care. **Meanwhile, here are some steps that YOU can take to obtain the best care NOW.**

How Do I Find Experienced Care Providers?

Choose a doctor with experience treating your type of cancer. Such a doctor will often be a board-certified oncologist, but other types of health care providers may specialize in the treatment of certain types of cancer. For example, urologists often treat prostate cancer and dermatologists treat many skin cancers.

Doctors involved in research may be able to offer you promising new treatments and provide access to clinical trials and other experimental programs.

Oncology researchers have devised many treatment plans and protocols based on the best available scientific evidence. Their use helps to ensure that you receive the best care supported by the latest scientific advances. Check to see if your health care providers are using the guidelines and protocols that are available for your situation.

If you need surgery or care that is considered “high-risk” – for example, surgery for cancer of the pancreas, esophagus, or for some types of lung cancer – consider getting care at facilities/hospitals with extensive experience in such procedures because they tend to have better outcomes.

How Do I Select and Evaluate My Doctor or Specialist?

By extension this also relates to your nursing care and the hospital or facility at which you will receive treatment.

- ❑ **Research the credentials of the professional(s) that will be handling your care.** Check their board certification(s) in the Official Directory of the American Board of Medical Specialties (ABMS) (available in the reference section at most libraries) or online at www.abms.org. The American Society of Clinical Oncology (ASCO) has a Website especially for consumers at www.cancer.net, which features an option to find certified oncologists by name, location and specialty (click on ASCO Resources, then Find an Oncologist).

- Check with your State Medical Board** – listed with the Federation of State Medical Boards at www.fsmb.org – or your local medical society.
- Ask about their education, specialty training and experience** – in years and number of procedures or cases similar to yours.
- Ask for referrals to other patients with a similar diagnosis who have given permission to be contacted.** Although it's tempting to ask a relative, neighbor, or friend for a referral, it is always best to do your own research to find a physician and/or cancer center that is suited to your illness and situation.
- Call the Cancer Information Service** toll-free at 800-4-CANCER (800-422-6237) for a listing of the National Cancer Institute's (NCI) designated Cancer Centers.
- Seek a second opinion.** Ask your physician for a referral to another specialist, or do your own research to find one.
- Other things to consider when making this decision:** your support system (family, friends), which may affect location, transportation, and access to other supportive care services such as counseling, rehabilitation and support groups.

How Do I Effectively Communicate with My Health Care Team?

- Evaluate the health care team's responsiveness** to your questions and their ability to effectively communicate about your diagnosis, treatment and other concerns.
- You are entering into a partnership with this team.** Ask who will coordinate your care—surgeon, medical oncologist, radiologist, or other specialist.
- Ask about accessibility.** Ask for a contact person (and phone number) of a case manager, nurse, or nurse practitioner who can speak with you during non-business hours.
- Be sure that you or your designated advocate understands** the medical terminology and the significance of scans, blood counts, other lab tests, and pathology reports.
- Ask about follow-up office policy:** How frequently will you be seen? where (in office, by phone)? when will lab tests and other results be reported to you (immediately, within a week)?

Understanding Your Diagnosis and Treatment Plan

“I was so frightened when first diagnosed. But I couldn’t stand feeling helpless so I decided I had to actively participate in the treatment I received. Doctors tend to treat symptoms; I insisted that my doctor treat me, the patient – the person. I insisted on a dialogue. When treatment was determined, I wanted to know the purpose, the side effects, and the alternatives. Then I researched everything. I don’t know if it can be measured, but I know it helped my recovery.”

Your doctor should tell you the kind of cancer you have, your prognosis and what you can expect from treatment. Your doctor should describe options for treatment and clearly set forth a treatment plan for you.

Understanding what cancer is and how your type of cancer can be treated will help you communicate with your health care providers and make decisions with confidence. Reliable information on cancer, its treatment and local supportive and treatment programs is available at no cost.

Cancer-related treatment usually consists of surgery, chemotherapy, radiation or a combination of these therapies. Newer, more targeted treatments for some diseases may have fewer side effects. Other new and emerging treatments – including hormones; biologics (cellular, protein and enzyme levels); immunosuppressors and others – are being researched in the laboratory and within clinical trials (see section on Clinical Trials).

Be sure that you understand all of your treatment options before starting any therapy. In most cases treatment doesn’t have to start immediately after diagnosis. Don’t rush to a decision, or let anyone else rush you. Your first treatment usually offers the best chance for cure, so it is important to know all of your options and the possible benefits and risks before that first treatment.

The National Cancer Institute, with input from patient advocates, lists the following questions for consideration *before* beginning treatment.

- Is there any evidence the cancer has spread? What is the stage of the disease?
- What are my treatment choices? Which do you recommend for me? Why?
- What new treatments are being studied? Would a clinical trial be appropriate for me?
- What are the expected benefits of each kind of treatment?
- What are the risks and possible side effects of each treatment?
- Is infertility a side effect of cancer treatment? Can anything be done about it?
- What can I do to prepare for treatment?
- How often will I have treatments?
- How long will treatment last?
- Will I have to change my normal activities? If so, for how long?
- What is the treatment likely to cost?

Understanding the Role of Clinical Trials in Quality Cancer Care

“I read about a promising new treatment for my cancer. When I asked my doctor, she told me that a clinical trial was being conducted to compare this drug to the standard treatment. If I agreed to participate I would receive the same quality of care (perhaps even better, because I would be very closely monitored) and I would be randomly assigned to receive either the standard drug or the new treatment. After reviewing the material she provided, comparing other potential treatments and trials and reading the informed consent document, I decided that this trial presented the best option for me and I agreed to participate.”

High-quality cancer clinical trials are an important component of quality cancer care. Before a new treatment method is made available to the public, it must undergo a clinical trial. Clinical trials, also called cancer treatment or research studies, test new treatments in people with cancer. Clinical trials test many types of treatment such as new drugs, new approaches to surgery or radiation therapy, new combinations of treatments, or new methods such as gene therapy.

Clinical trials are strictly monitored and carefully evaluated to test the therapy's safety and efficacy (effectiveness). Any new treatment must successfully complete three phases of trials (see www.cancer.gov/clinicaltrials for a complete guide and description of Phase I, II and III trials) before the federal Food and Drug Administration (FDA) approves it for general use.

It's important to know that *every patient* in a Phase III trial receives either the standard treatment for a specific cancer or the treatment being investigated. The common misperception that some patients receive placebos has kept many patients from participating in cancer clinical trials.

Is it right for me?

Of course, there is no guarantee that a new treatment being tested or a standard treatment will produce good results. New treatments also may have unknown risks.

In the past, clinical trials were sometimes seen as a last resort for people who had no other treatment choices. Today, patients with common cancers often choose to receive their first treatment in a clinical trial.

How do I decide?

A number of excellent publications and Websites address this question. Reference the Patients section of the Coalition of National Cancer Cooperative Groups at www.cancertrialshelp.org. Before making a final decision, review the National Cancer Institute booklet *If You Have Cancer: What You Should Know About Clinical Trials* or check the information and questions at www.cancer.gov/clinicaltrials/learning and click on [Participating in a Trial: Questions to Ask Your Doctor](#).

These important questions must be asked and answered to your satisfaction before you can make this decision. If you agree to participate, you will receive a copy of the written description of the trial. You will also be provided with an informed consent document that you must sign, indicating that you understand the trial and what will be required to participate.

Insist on Comprehensive, Coordinated and Continuous Care

Good cancer care involves doctors, nurses, social workers and other providers working as a team throughout your care.

Make sure that one member of your medical team is designated as your advocate to coordinate your care and guide your progress throughout treatment.

If you experience pain or symptoms such as fatigue or nausea, ask for assistance. Effective treatments are available for many of the symptoms of cancer and for the symptoms caused by cancer treatment.

Psychological counseling, social services and rehabilitation are among the support services that should be available to you. Maintain contact information to access the support you may need.

Demand a Lifetime of Excellent Care

You should feel comfortable asking questions and talking to your medical providers. Make sure they listen to you and respect your point of view. Your decisions and your dignity should be respected.

If you need assistance in finding care or alleviating medical costs, you may find help through support and volunteer groups such as Cancer Care, Inc., and the American Cancer Society.

If your doctor tells you your cancer is incurable, ask questions. Even if a cure is not possible, there may still be treatments that can prolong life significantly, as well as procedures to reduce pain and other symptoms. In fact, most symptoms associated with cancer care and treatment can be managed well. This is one area where your advocacy may require persistence as these symptoms vary from individual to individual. (See Section on Symptom Management on page 17 for more specific information).

Sometimes, in holding out *hope*, either doctors or patients may insist on very aggressive or controversial treatment when there is little chance that the treatment will prolong life. The option of hospice care may be overlooked, but should be considered because it can often offer individuals dying of cancer comfort and resources beyond what doctors and family alone can provide.

**Once you reach a decision, based on sound knowledge
and good research, don't second-guess yourself!**

INSURANCE AND EMPLOYMENT RIGHTS

“It was such a relief to know that there was information specifically for people with cancer available on insurance and employment issues. Once I knew what my rights were in the workplace and under my state’s insurance laws, I could concentrate on getting the best possible cancer care.”

The maze of bureaucracy and paperwork may seem overwhelming, but it is important to know and understand your rights as a cancer survivor under existing state and federal laws. Be aware that health insurance coverage and employment protections are not consistent and may depend on your age, the state in which you live, the size of your employer and other variables. However, an alphabet soup of federal laws, a few of which are presented below, may provide some protection. Other NCCS publications deal with these subjects at length. (See Resources)

The Americans with Disabilities Act (ADA)

The Consolidated Omnibus Budget Reconciliation Act (COBRA)

The Federal Rehabilitation Act (FRA)

The Health Insurance Portability and Accountability Act (HIPAA)

- Read and understand your health insurance policy or check with your broker or benefits coordinator about your coverage.
- If you do not have insurance, check with your state insurance office about other possible coverage, high-risk pools and other options.
- To get information about coverage under Medicare and Medicaid, contact the Centers for Medicare & Medicaid Services (CMS) at 800-MEDICARE (800-633-4227). Reference NCCS’ *What Cancer Survivors Need to Know About Health Insurance*.

If you are a working woman with cancer, try www.cancerandcareers.org for additional information. For both men and woman in the workplace, read NCCS’ newly revised booklet *Working It Out: Your Employment Rights As a Cancer Survivor*. We cannot overemphasize that although situations and conditions vary, state and federal laws and regulations may protect you if you know your rights.

ONGOING SELF-ADVOCACY

“I thought when my active treatment was over, I would return to life as if nothing had happened. I now realize that I must be proactive and vigilant about my care and my health for the rest of my life.”

Although suggestions for being a self-advocate have been presented during and after treatment, in actuality you must now be an advocate for the balance of your life – not only to receive the care and monitoring that you require, but the social and support services that may be needed.

DURING TREATMENT

There is no reason to unnecessarily suffer from the effects of treatment or from the disease itself. There have been many advances in the management of nausea, pain, fatigue, weight loss and depression. Many side effects are not visible and, unless voiced by you, will remain untreated. Doctors often say that these problems are not reported to them and are therefore untreated or ignored.

It is important that you now monitor your body, your psyche and its changes during and after your treatment for cancer. Keep a record or journal of your treatments and your physical, emotional and mental state – using a measurable scale. This can be as simple as measuring the intensity of a symptom on a scale from 1 to 5. Ask if your doctor or hospital has already developed such a system for patients. A written record provides a basis of comparison or can indicate a pattern. You can then take corrective action. For example, you may feel well and energetic in the morning, but end up getting your treatment in the late afternoon when you feel weakest. Just by changing the time of your treatment, you may see an immediate difference in your reaction and rate of recovery. **Survivors and their supporters report that you can improve your ability to cope and your quality of life if you:**

- Strongly insist on having a nurse and/or case manager assigned to you and available after hours.
- Select one family member or friend as your representative if you are unable to speak for yourself. Be sure to inform your health care team in advance.
- Articulate your symptoms to your doctor. Don't wait to be asked! If necessary, use your journal as documentation.
- Avail yourself of professional and/or peer support and self-help groups.

AFTER TREATMENT AND FOR THE BALANCE OF LIFE

Now, and for the rest of your life, you must be self-aware, as others cannot, about subtle and not so subtle changes in symptoms such as pain, weakness, fatigue, or loss of appetite.

Take advantage of cancer support services such as pain management clinics; insurance and financial aid-assistance, psychological counseling and therapy. If such services are unavailable, then advocate for support and referrals in order to receive these services.

- Stay informed about new research and developments in the treatment or late effects of your type of cancer. (See long-term and late-effects following this section)
- Attend community cancer programs or participate in teleconferences and webcasts that provide credible and current information.
- Ask your doctor(s) for a written summary of the treatment(s) received; drugs, dosage, amount of radiation, etc. Maintain this record with your health documents and present it to any new treating physician(s).
- Be vigilant about monitoring your own health. Have regular check-ups and talk with your doctor about secondary prevention and monitoring for late effects of treatment.

LONG-TERM AND LATE EFFECTS

Survivorship statistics are encouraging, but you may be unaware of potential delayed side effects of the illness and its treatment. This is increasingly important as the number of long-term survivors increases. Currently, follow-up clinics exist primarily for survivors of childhood cancer.

Over the past several years the Institute of Medicine has published several reports on the status of survivorship research. These reports include: *Childhood Cancer Survivorship: Improving Care and Quality of Life* (2003); *From Cancer Patient to Cancer Survivor: Lost in Transition* (2005); and *Cancer Care For the Whole Patient: Meeting Psychosocial Health Needs* (2007).

These reports demonstrate that after a diagnosis of cancer there is an increased risk of a recurrence (reappearance of disease) or metastases (transmission to other sites in the body), or of a second primary tumor. There are also other increased risks that vary based on a particular diagnosis and treatment.

Since its inception, NCCS has advocated for research and long-term follow-up for adult cancer survivors. As early as 1987, a leading oncologist in survivorship research, Dr. Patricia A. Ganz, wrote:

- Familiarize yourself with the specifics of your treatment**
- Remain alert to the possibility of secondary medical effects**
- Plan to have regular follow-up visits for the rest of your life**

These suggestions are as true today. There is now evidence that treatment may cause or contribute to long-term or subsequent physiologic changes as long as 5, 10, or 20 plus years later. This is not intended to frighten you, but rather to alert you to the potential problems so that you can be vigilant about your care.

Simply by aging, many of us experience these health problems. Organ damage, organ failure, premature infertility, premature aging, compromised immune system and a damaged endocrine system have been identified as some of the potential immediate, mid-range and long-term effects. These effects may contribute to chronic illness, incontinence, swelling, reproductive problems and psychological conditions. You can exercise control if you:

- Know the risk factors and learn how to prevent or reduce them.**
- Follow Dr. Ganz's advice above.**

SYMPTOM MANAGEMENT THROUGHOUT THE LIFESPAN

The concept of symptom control and adequate pain management from the moment of diagnosis, rather than only at the end stages of disease, is important and empowering for cancer survivors. You can improve the quality of your life to the extent that you can alleviate and manage the side effects of your cancer and its treatment.

The most commonly used term to describe symptom management is *palliation* or *palliative care*. While many people associate these terms with *end-of-life care*, NCCS believes palliative care is essential from the moment of diagnosis through the balance of life.

WHAT IS PALLIATIVE CARE?

In 2001, the National Cancer Policy Board adopted the World Health Organization (WHO) definition of palliative care in cancer “*as active total care of patients whose disease is not responsive to curative treatment.*” The Board issued a groundbreaking report – *Improving Palliative Care for Cancer*. The report went on to state that “palliative care focuses on addressing the control of pain and other symptoms, as well as psychological, social, and spiritual distress.” But perhaps most importantly it focused “**on the importance of palliative care beginning at the time of a cancer diagnosis and increasing in amount and intensity throughout the course of a patient’s illness, until death.**”

Interestingly, the report identified six major skill sets for total and complete palliative care. With the exception of the last skill, you have been developing these skills throughout this handbook.

- Communication
- Decision-making
- Management of complications of treatment and the disease
- Symptom control
- Psychosocial care of patient and family, and
- Care of the dying

Although palliative care is beginning earlier and moving into the mainstream of quality cancer care, you may have to be proactive in demanding it for yourself or for loved ones. Much of this care is not reimbursed adequately, which partially accounts for it being undervalued by treating professionals.

END OF LIFE

While cancer survival has improved dramatically over the past few decades, a diagnosis of cancer often raises, for the first time, the prospect of a premature death. In our culture, we have been reluctant to discuss death or plan for it. Our technological progress, medical training, and progressive health care mindset seek to save lives at almost any cost. Neither doctor nor patient nor family and friends feel comfortable raising the issue of dying. Consequently, when death appears to be an inevitable outcome of cancer that is no longer responding to active treatment, we often fail to provide a good way to help ourselves, or someone we love, die well.

NCCS has been actively addressing the issue of this last stage of survivorship. Inevitably, with half of all cancer diagnoses, there will come a time when no treatment options exist or the prognosis for extended survival is poor. Former NCCS President Elizabeth Clark, PhD, has researched and written extensively about grief and bereavement. She is the author of NCCS' *You Have the Right to Be Hopeful*. She writes: "Hope is flexible, and it remains open to various possibilities and the necessity to change the desired outcome as the reality changes." *You Have the Right to Be Hopeful* presents the many and changing meanings of hope – among which is the "hope for a dignified death."

The advocacy skills of information seeking, communication, problem solving and negotiation take on special importance when making decisions about discontinuing treatment or how and where you wish to die.

Recent studies show that people become more comfortable and appear to die more peacefully when they have planned for their death in advance and communicated these wishes to others.

At the end of life one can still be proactive if provisions have been made in advance. In 1990, the United States Supreme Court ruled that the Constitution gives individuals the right to control their own medical care, however, you must provide "clear and convincing evidence of your desires in the form of an advance health care directive."

- Educate yourself about end-of-life issues and advanced care planning (medical living wills and durable powers of attorney that vary by state). Contact Choice in Dying at 800-989-WILL (800-989-9455) or www.partnershipforcaring.org for information and state-specific forms. The National Cancer Institute and the American Cancer Society, among others, are updating materials for people with advanced cancer. NCCS also offers a program to address end of life issues in its Cancer Survival Toolbox[®] program.
- Meet with experts in this type of planning: a peer counselor, hospital social worker, a spiritual or bereavement counselor, or a hospice representative.
- Prepare a will and put your affairs, legal and otherwise, in order.
- Make your wishes known in advance. Choose someone to act as your proxy that will be willing and able to carry out your wishes.

Fortunately, many of us will go on to lead long, satisfying and meaningful lives after a cancer diagnosis. This opportunity may lead to interest and involvement in other kinds of cancer advocacy.

OTHER TYPES OF CANCER ADVOCACY

You need not confine your advocacy to a personal context. After a cancer experience, many people or their family members and friends feel a need to “get involved.” You can expand your participation in many ways.

Community advocacy can begin simply by assisting others through the cancer experience – “the veteran helping the rookie” – or by speaking about your experience to others. It can include public speaking or writing, distribution of flyers, assistance with fundraising for your support group or hospital, or having a cancer survivor’s day petition signed by the mayor or governor. You can also get involved with an advocacy group in your town or city – many national organizations have state and regional offices that work locally – at the *grassroots* level to accomplish change. You can be active at the community level by participating in support groups, planning informational programs and Survivors Day events and by planning or participating in a Town Hall meeting.

National advocacy or public policy on behalf of social issues is referred to as public interest advocacy. NCCS was actually founded out of a community-based peer-support organization, People Living Through Cancer, in Albuquerque, New Mexico. But the founders intended and envisioned NCCS as an organization that would lead and strengthen the survivorship movement, inform this constituency and advocate on their behalf. To become a more effective national advocate, NCCS moved from New Mexico to the greater Washington area, increasing our ability to interact with government agencies, Congress and The White House.

There are many ways to get involved at the national level, from public testimony to getting out the vote. NCCS has accomplished many things in its short history, but many challenges remain. **We invite you to join us at www.canceradvocacy.org to change attitudes and policies about cancer.**

NCCS AND ADVOCACY

The National Coalition for Cancer Survivorship (NCCS) was founded in 1986 by a small group of committed patients, family members and health care professionals. NCCS's co-founder and first president, Fitzhugh Mullan, MD, recognized that “surviving is a potent idea, but one that has been paid little heed in the field of cancer treatment.”

The preamble of this new organization's charter stated that, “From the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor.” This was contrary to the medical-model definition of a survivor as someone who has been cancer-free for five years after treatment. NCCS's “patient-centered” focus and involvement in issues that affected survivors' lives marked a change in previously held perceptions and attitudes about people with cancer. It also served to take patients and their loved ones from a state of limbo and passivity into one of personal empowerment. NCCS advocated for this change in perception and language by developing the concept of *cancer survivorship* – “the experience of living with, through or beyond cancer” – and expanded the definition of survivor to include family, friends, and caregivers. NCCS also recognizes that even with terminal illness, an individual continues to survive in the hearts, minds and memories of this extended family.

The Office of Cancer Survivorship (OCS) at the National Cancer Institute was established in 1996 as a direct result of NCCS's First National Congress on Cancer Survivorship and its culminating report: *Imperatives for Quality Cancer Care: Access, Advocacy, Action and Accountability*.

Not only was NCCS instrumental in the creation of the Office of Cancer Survivorship, but NCI and OCS have adopted NCCS's definition of a cancer survivor.

While these achievements represent significant milestones of cancer advocacy, we understand that individuals diagnosed with cancer confront very personal issues and decisions. We hope that you have found this handbook helpful in providing tools and resources to assist, strengthen and empower you – for ultimately that is what self-advocacy is all about.

The
Cancer
Survivors'

Bill of Rights

written by Natalie Davis Spingarn

The National Coalition for Cancer Survivorship presents this...*Survivors' Bill of Rights* to call public attention to survivor needs, to enhance the quality of cancer care, to empower cancer survivors, and at the same time bring greater satisfaction to them and their physicians, employers, families, and friends.

Survivors have the right to continuous lifelong medical care, as needed. The physicians and other professionals involved should make every effort to be:

- ↻ *sensitive* to cancer survivors' lifestyle choices and their need for self-esteem, dignity and privacy of the information trusted to them;
- ↻ *careful*, no matter how long these patients have survived, to take symptoms seriously and not to dismiss aches and pains, for fear of recurrence is a normal part of survivorship;
- ↻ *vigilant* to watch for any long-term and late effects of cancer and its treatment in follow-up clinics and offices;
- ↻ *informative* and open, providing survivors with as much or as little candid medical information as they wish, and encouraging informed participation but not expecting survivors to manage that care on their own;
- ↻ *knowledgeable* about counseling and rehabilitation resources...

No matter in which setting their care is offered-be it fee-for-service or some sort of managed care system- survivors have the right to quality care emphasizing:

- ↻ *informed choice* - choice of the setting in which care is delivered, choice of primary physicians and specialists delivering that care, as well as choice of appropriate, effective and safe treatments (including ongoing clinical trials);
- ↻ *efficient yet humane management* of such unfortunate by-products of disease as fatigue and pain...
- ↻ *appropriate use of hospital and other facilities*, wherein cost effectiveness and patient-centered care are balanced ...
- ↻ *constant respect for survivors' wishes* as to when and how to discontinue treatment should that time arise, including the scrupulous honoring of "living wills" and similar documents.

In their personal lives, survivors, like other Americans, have the right to the pursuit of happiness. This means they have the right:

- ↻ *to talk* with their families and friends about their cancer experience if they wish, but to refuse to discuss it if that is their choice...
- ↻ *to be free* of the stigma of cancer as a "dread disease"...
- ↻ *to be free* of blame for having the disease and of guilt for having survived it;
- ↻ *to participate* in support groups and other survivor support and/or advocacy activities as they wish...

In the work place, survivors have the right to equal job opportunities. This means they have the right:

- ↻ *to aspire to jobs* worthy of their skills, and for which they are trained and experienced, and thus to not have to accept jobs they would not have considered before their cancer experience;
- ↻ *to be hired, promoted, and accepted* on return to work, according to their individual abilities and qualifications, and not according to "cancer" or "disability" stereotypes, with "reasonable accommodation," under federal and state law...
- ↻ *to privacy* about their medical histories.

Since health insurance is an urgent survivorship concern, every effort should be made to assure all survivors decent, affordable coverage, whether public or private, or provided under managed care or fee-for-service systems. This means:

- ↻ *for employers*, that survivors have the right to be included in group health coverage...
- ↻ *for physicians, counselors, and other professionals concerned*, that they keep themselves and their survivor-clients informed and up-to-date on the dangers of health insurance discrimination...
- ↻ *for social policy makers*, both in government and in the private sector, that they seek both to broaden insurance programs to include diagnostic procedures and treatments which help prevent recurrence and ease survivor anxiety and pain, as well as to lower the unfair barriers often imposed by the accidents of race, minority culture, age, or plain lack of means to pay for adequate health insurance coverage.

In sum, cancer survivors have the overriding right to access quality health care. Implicit in that right is universal access to adequate health insurance coverage. For "quality" becomes an empty word without the means to achieve such coverage. A cancer may not even be discovered. And if it is, care may be sub-optimal, no one will be accountable for it, and the whole society will be the losers.

RESOURCES

NCCS provides these resources for informational purposes only and is not responsible for the information provided by the organizations listed. For medical questions, please consult your physician. This list is by no means all-inclusive. Please refer to our interactive Resource Guide at www.canceradvocacy.org or call NCCS at 877-NCCS-YES (877-622-7937).

National Coalition for Cancer Survivorship

<http://www.canceradvocacy.org>
877-NCCS-YES (622-7937)

- General Resources

About Face

<http://www.aboutfaceusa.org>
888-486-1209

- Oral, Head and Neck

American Association of Retired People

<http://www.aarp.org/life/caregiving>
800-424-3410

- Caregiving/Family Support
- Older Persons

American Association of Sex Educators, Counselors & Therapists

<http://www.aasect.org>
319-895-8407

- Fertility & Sexuality

American Brain Tumor Association

<http://www.abta.org>
800-886-2282

- Brain

American Cancer Society (ACS)

<http://www.cancer.org>
800-ACS-2345 (227-2345)

- General Resources
- Insurance/Financial Assistance

American Chronic Pain Association

<http://www.theacpa.org>
916-632-0922

- Pain Management

American Foundation for Urologic Disease

<http://www.afud.org>
800-828-7866

- Prostate

American Pain Foundation

<http://www.painfoundation.org>
888-615-PAIN (7246)

- Pain Management

Blood & Marrow Transplant Information Network

<http://www.bmtnews.org>
888-597-7674

- Bone Marrow Transplants

The Brain Tumor Society

<http://www.tbts.org>
800-770-8287

Breast Cancer Network of Strength

<http://www.networkofstrength.org>
800-221-2141

- Breast

Cancer.net

<http://www.cancer.net>
571-366-9537

- General Resources

Cancer Care, Inc.

<http://www.cancercare.org>
800-813-HOPE (4673)

- General Resources
- Patient Support

Cancer Hope Network

<http://www.cancerhopenetwork.org>
877-HOPENET (467-3638)

- Patient Support

Cancer Information Service (National Cancer Institute)

<http://www.cancer.gov>
800-4-CANCER (422-6897)

- General Resources

Candlelighters Childhood Cancer Foundation

<http://www.candlelighters.org>
800-366-2223

- Pediatric & Young Adult

The Children's Cause For Cancer Advocacy

<http://www.childrenscause.org>
301-562-2765

- Pediatric & Young Adult

Coalition of National Cancer Cooperative Groups

<http://www.cancertrialshelp.org>
877-520-4457

- Clinical Trials

Colon Cancer Alliance

<http://www.ccalliance.org>
877-422-2030

Family Caregiver Alliance (FCA)

<http://www.caregiver.org>
800-445-8106

- Caregiving/Family Support

Fertile Hope

<http://www.fertilehope.org>
888-994-HOPE

- Fertility & Sexuality

Genetic Alliance

<http://www.geneticalliance.org>
202-966-5557

Gilda's Club Worldwide

<http://www.gildasclub.org>
888-GILDA-4-U

- Patient Support

Gynecologic Cancer Foundation

<http://www.wcn.org/gcf/>
800-444-4441

- Information & Specialist Directory

Hospice Foundation of America (HFA)

<http://www.hospicefoundation.org>
800-854-3402

- Bereavement

Intercultural Cancer Council (ICC)

<http://www.icc.bcm.tmc.edu>
713-798-4617

- Minority/Special Population

International Myeloma Foundation

<http://www.myeloma.org>
800-452-2873

- Multiple Myeloma

Kidney Cancer Association

<http://www.kidneycancerassociation.org>
800-850-9132

Lance Armstrong Foundation

<http://www.laf.org>
512-236-8820

- Education and Research

Let's Face It

<http://www.faceit.org>
360-676-7325

- Oral, Head and Neck

The Leukemia & Lymphoma Society

<http://leukemia-lymphoma.org>
800-955-4572

Lung Cancer Alliance

<http://www.lungcanceralliance.org>
800-298-2436

- Lung

Lymphoma Research Foundation (LRF)

<http://www.lymphoma.org>
800-500-9976

Melanoma Research Foundation

<http://www.melanoma.org>
800-MRF-1290 (673-1290)

Multiple Myeloma Research Foundation

<http://www.multiplemyeloma.org>
203-972-1250

National Bone Marrow Transplant Link

<http://www.nbmtlink.org>
800-LINK-BMT (546-5268)

- Bone Marrow Transplants

National Brain Tumor Foundation

<http://www.braintumor.org>
800-934-CURE (2873)

National Breast Cancer Coalition

<http://www.natlbcc.org>
800-622-2838

National Cancer Institute (NCI)

<http://www.cancer.gov>
800-4-CANCER (422-6897)

- Research & Information
- Clinical Trials

National Childhood Cancer Foundation (NCCF)

<http://www.curesearch.org>

800-558-6223

National Family Caregivers Association

<http://www.nfcacares.org>

800-896-3650

- Family Support

National Hospice & Palliative Care Organization (NHPCO)

<http://www.nhpc.org>

800-658-8898

- Hospice & Bereavement

National Lymphedema Network

<http://www.lymphnet.org>

800-541-3259

National Organization for Rare Diseases (NORD)

<http://www.rarediseases.org>

800-999-6673

- Rare/Orphan Cancers

National Ovarian Cancer Coalition

<http://www.ovarian.org>

800-OVARIAN (682-7426)

National Partnership for Women and Families

<http://www.nationalpartnership.org>

202-986-2600

- Employment Rights
- Healthcare

Ovarian Cancer National Alliance

<http://www.ovariancancer.org>

202-331-1332

Ovarian Cancer Research Fund, Inc.

<http://www.ocrf.org>

800-873-9569

Pancreatic Cancer Action Network (PanCAN)

<http://www.pancan.org>

877-2-PANCAN (272-6226)

Patient Advocate Foundation

<http://www.patientadvocate.org>

800-532-5274

- Insurance/Financial Assistance

Prevent Cancer Foundation

<http://www.preventcancer.org>

800-227-2732

- Prevention
- Research

Sisters Network

<http://www.sistersnetworkinc.org>

713-781-0255

- Breast - African American

Susan G. Komen For The Cure

<http://www.komen.org>

800-IM-AWARE (462-9273)

- Breast

Thyroid Cancer Survivors' Association (THYCA)

<http://www.thyca.org>

877-588-7904

The Ulman Cancer Fund For Young Adults

<http://www.ulmanfund.org>

800-393-FUND (3863)

- Pediatric & Young Adult

United Ostomy Association

<http://www.uoa.org>

800-826-0826

- Bladder
- Colorectal

US TOO International

<http://www.ustoo.org>

800-808-7866

- Prostate

The Wellness Community

<http://www.thewellnesscommunity.org>

888-793-WELL (793-9355)

- Patient Support

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Cancer Survival Toolbox[®], developed by NCCS in collaboration with the Oncology Nursing Society, the Association of Oncology Social Work and the National Association of Social Workers. Available free of charge in English and Spanish. Listen or read the transcripts of the program online at www.canceradvocacy.org/toolbox or order a free hard copy by calling 877-NCCS-YES (622-7937).

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Working it Out: Your Employment Rights As a Cancer Survivor, by Barbara Hoffman, JD. Published by the National Coalition for Cancer Survivorship. Eighth Edition (2008), 22pp. Available in English and Spanish.

You Have the Right to Be Hopeful, by Elizabeth J. Clark, Ph.D. Published by the National Coalition for Cancer Survivorship. Fourth Edition (2008), 24 pp. Available in English and Spanish.

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NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

NATIONAL COALITION FOR CANCER SURVIVORSHIP
1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910
877.NCCS.YES
www.canceradvocacy.org