



Coping With Cancer on the East End

*A Practical
Resource Guide*

2011

Compiled by

FIGHTING CHANCE

*Free Cancer Counseling Center
Serving the East End . . . since 2002*

Sag Harbor, New York; www.fightingchance.org; email: info@fightingchance.org

USING THIS GUIDE

Understanding how to use this guide starts with understanding Fighting Chance and how we think about coping with cancer.

As healthcare providers, cancer survivors and caregivers of loved ones, we believe that coping with cancer begins with you.

Who you are, your hopes and dreams, your community of family and friends will be your life preserver.

Creating that life preserver may feel daunting right now. Fighting Chance aims to make this process easier by helping you answer your most pressing questions:

- How can I mobilize my resources?
- What is my game plan?
- How can I get organized?
- What is the best way for me to set priorities and make the wisest choices?

People coping with cancer face common challenges. Each of the 17 chapters in this guide explains these hurdles and provides practical suggestions for dealing with them.

If you have been told you have cancer... think
Fighting Chance

BOARD OF DIRECTORS

Peter Bach, M.D. is a pulmonologist/intensivist with expertise in quality of care and epidemiologic research methods at Memorial Sloan-Kettering Cancer Center. With his wife, Ruth, they split their time between their homes in Sag Harbor and Brooklyn.

Steve Byers has had a distinguished career in journalism, including the post of Editor-in-Chief of *National Geographic/Adventure* where he also developed films and books under the National Geographic imprint. He resides in both Sag Harbor and New York City with his wife, Heather Kilpatrick. Two of Steve's family members died of cancer.

Tony Brandt is a long-time resident of Sag Harbor and noted essayist, whose most recent work includes editing the journals of Lewis and Clark...his brother battled cancer.

Duncan Darrow is a lawyer who splits his time between New York and Sag Harbor. His mother died of cancer six years ago, helping to inspire his involvement in the field of cancer care by enlisting community volunteers...also trained as a hospice volunteer.

Sue Davies is a prominent member of the East Hampton community and supportive of many local organizations for years; her mother recently died of cancer. Sue has extensive experience with cancer care challenges on the East End.

Ben Gillikin has been a senior executive in the cosmetics industry for the past 38 years. Recently he retired from corporate life to pursue new business ventures. With his wife, Deb, they are now spending more time in their East Hampton home...his sister recently battled cancer.

Tuck Hardie is a Senior Partner in the investment banking firm of Houlihan Lokey and has spent summers in Amagansett. He has been a critically important caregiver to family members who have been touched by cancer.

Renu Hausen, M.D. is a board-certified radiation oncologist and the director of North Fork Radiation Oncology located in Riverhead. She is a member of the medical staffs of Southampton Hospital, Peconic Bay Medical Center, and Eastern Long Island Hospital. She has been serving patients on both the North and the South Forks since 1999.

Martin S. Karpch, Jr., M.D. is the Chairman of the Department of Surgery and the Director of Surgical Oncology at Beth Israel and St. Luke's-Roosevelt Hospitals in New York City. Dr. Karpch, his wife, Julianne, and their children split their time between homes in New York City and Shelter Island.

Lisa Matlin with her husband, David, and her child the Matlin Family splits their time between an apartment in New York and a home in the Hamptons. Lisa has had successful careers in Financial Services and Specialty Retailing and is on the Board of several non-profit groups.

Barbara McLaughlin is an active member of Memorial Sloan-Kettering Cancer Center's fundraising arm known as the Society. With her husband, Kevin, and their children, Barbara splits her time between homes in Sag Harbor and New York City.

Cathy Peacock, who has enjoyed a successful career in the financial services industry.

Richard Perlman is one of Wall Street's most innovative investors and turnaround experts. Richard and his wife, Ellen, split their time between Sag Harbor, New York City and Sun Valley and have been generous supporters of many community initiatives on the East End.

Rosemarie Slevin Perocchia, RN has managed a staff of over thirty cancer information specialists who were a central feature of a national "helpline" for cancer patients, sponsored by the National Cancer Institute.

Ed Tirrell, a Wall Street executive for 25 years now living in Texas with his wife and son, often visits the East End. Both his parents died of cancer and Ed has an abiding interest in cancer care issues.

Staff

Karrie Robinson, LCSW-R *Director, Clinical Programs
and Oncology Social Worker*

William Di Scipio, Ph.D. *Clinical Psychologist*

Margaret Bromberg, LCSW-R..... *Oncology Social Worker*

Maxa Luppi..... *Cancer Patient Navigator*

C.B. Grubb *Graphic Design & IT Support*

Vanessa Petrucci..... *Director of Internet Outreach*

Maureen McAdam *Volunteer Coordinator*

Friends of Fighting Chance

A growing group of individuals and businesses contribute from \$50 to \$5,000 each year to help ensure that this Guide, the website and outreach support provided by Fighting Chance are made available free of charge to our community. As a Friend, you will receive our bi-annual newsletter and receive invitations to special events.

Fighting Chance is a 501©(3) organization, and all contributions are fully tax-deductible. (Tax ID: 02-0536368). Checks can be made payable to Fighting Chance and sent to us at P.O. Box 1358, Sag Harbor, New York, 11963. Donations can also be made via credit card either on our website (www.fightingchance.org) or by calling our office at (631) 725-4646.





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CHAPTER 1

FIGHTING CHANCE

COUNSELING AND RESOURCE CENTER FOR CANCER PATIENTS



The East End of Long Island is a unique geographic region composed of dramatic coastlines and vast farmland. However, as beautiful as this rural setting is, it can present challenges to those diagnosed with cancer and their families. For example, the distances one must travel for doctor's appointments, coupled with the limited availability of mass transit, can often leave those in need feeling isolated within their own community.

Challenge: Where, in my community, can I go for information and support to help me deal with my cancer?

Solution: Visit the Fighting Chance office in Sag Harbor, where you can obtain a variety of educational resource materials tailored exclusively for cancer patients and their caregivers. We provide educational materials about various types of cancer and how to cope with the disease. We also offer individual counseling and family support. Call our office to make an appointment today.

Opened in 2002, Fighting Chance helps patients, family members, and caregivers find accurate medical information, locate resources, and develop strategies to cope with the impact of cancer.

Services at Fighting Chance

Counseling

A cancer diagnosis challenges people physically, emotionally and socially. At Fighting Chance we are dedicated to providing free professional counseling services for people affected by cancer. We have licensed oncology social workers who are trained to understand the basic biology of cancers, and how diagnosis, treatments and the aftermath impacts the patient as well as the family. Our social workers offer short-term individual, family, and group counseling sessions that enable people to discuss concerns and solve problems in a safe and respectful environment.

Educational Support Group

Fighting Chance offers an educational support group for patients at the Sag Harbor Office. Our clinicians encourage supportive discussions on topics such as health concerns,

Chapter One: **Fighting Chance**

health maintenance, emotional and relationship issues, resource finding and problem solving. Our group gives patients the chance to feel less alone and share feelings that are common to the cancer experience. Please call the Fighting Chance office at (631-725-4646) to register for the next group meeting.

Patient Navigation

Having cancer can present a series of crises, beginning from the day of diagnosis through treatment and beyond. The patient navigator assists patients, family members and caregivers overcome obstacles throughout the cancer journey. At Fighting Chance, the patient navigator is the first line of contact for patients and caregivers. The patient navigator assists with such issues as providing information on the particulars of a specific disease, locating physicians and medical facilities, troubleshooting transportation and financial issues, and addresses concerns about insurance and employment.

Patient Educational Workshops & Lectures

As our understanding of cancer has improved dramatically over the past decade, the patient population insists on becoming more informed and assertive as medical consumers. Through our periodic educational workshops, patients will gain state-of-the-art knowledge from expert speakers, feel more in control of their illness, and ultimately feel more empowered as a consumer. Typical workshop subjects include: fitness and strength, diet and nutrition, enhancing family communication, mind/body medicine, employment concerns, and maximizing health benefits. We also offer creative wellness workshops that include photography and writing that help patients document their cancer journey.

Patient Resource Library & Reading Room

In putting together this resource guide, *Coping With Cancer on the East End*, we researched websites, informational guides and numerous other sources. Through this search, we have acquired a wide selection of pamphlets on the many types of cancers, as well as information on treatment side effects, and coping tips. If you call our office in Sag Harbor (631-725-4646), our staff can assemble a package of material that relates to your specific cancer and guide you to the most useful websites. Feel free to come in and browse through our selection.

In battling cancer, you have to start somewhere. Fighting Chance is a good place to start!



DOCTORS



Dealing with cancer means dealing with doctors, oftentimes many doctors. So, selecting a network of people to be on your medical team, to include as part of your life preserver, is crucial for both your physical *and* emotional health.

Challenge: How do I find the right doctor(s) for me?

Solution: If you are reading this guide, most likely you or your loved one has already been diagnosed with cancer. In many cases a primary care physician refers patients to an oncologist, who is a physician specializing in the treatment of cancer.

The focus in this chapter is on doctors who treat cancer. Doctors who most often provide treatment of cancer are surgeons, medical oncologists and radiation oncologists. Radiologists may follow the treatment using CT scans, MRI, bone scans and PET scans to help monitor the patient's progress. The most common forms of treatment for cancer include surgery, chemotherapy, radiation therapy, immunotherapy (biologic therapy) and cell targeted therapies.

Surgery involves removing cancerous tissue/tumors from the body.

Chemotherapy is the use of a chemical agent to attack and kill cancerous cells. Chemotherapy can be administered intravenously and orally and may be received in a hospital, an outpatient doctor's office or in the home.

Radiation Therapy is the use of high dose x-rays to kill cancer cells. Typically, radiation therapy is given on an outpatient basis in hospitals or radiation treatment centers.

Immunotherapy, also know as biologic therapy, is treatment to stimulate or restore the ability of your body's immune system to fight cancer. Immunotherapy can also be given to lessen the side effects of certain cancer treatments.

Cell Targeted Therapy uses drugs that block the growth and spread of cancer by interfering with specific molecules involved in the process by which normal cells become cancer cells and tumor growth.

Selecting Your Medical Team

As you begin your search for a doctor, be sure to check his/her credentials. One way to do that is to ask your doctor if he or she is Board Certified. Becoming a licensed, Board Certified physician means meeting the most rigorous training and continuing education standards offered in the field of medicine.

Certification of physicians is done by medical specialty boards, recognized by the American Board of Medical Specialties (ABMS) and the American Medical Association (AMA). This is a way to tell consumers that the doctors with these credentials have successfully completed approved training and have passed an evaluation process assessing their ability to provide quality patient care in their specialty.

Board certification is time-limited. To maintain certification, doctors are periodically reevaluated. They must present evidence of licensure and the scope of their practice and pass an examination every seven to ten years, depending on the specialty.

Board certification is a good indication that your doctor has made a commitment to continuing education and is keeping up with the latest findings in his or her field.

Check the “Physician Select” service of the website of the American Medical Association. This gives you lists of doctors, by specialty, who practice near you. You can also check on training and board certification at: <http://www.ama-assn.org/aps/amahg.htm>. (*Source www.webmd.com*)

You can also find oncologists through the American Society of Clinical Oncologists (ASCO). ASCO is a worldwide professional organization representing physicians who diagnose and treat people with cancer. The doctors of ASCO set patient care standards and lead the way for research and treatment of cancers around the world. ASCO recommends the following guidelines when choosing an oncologist and treatment facility:

- Choose an oncologist with broad experience in the treatment of your particular cancer.
- Choose a hospital/medical facility that sees a large volume of patients and conducts clinical research, including clinical trials.
- Choose an oncologist who belongs to ASCO or other professional societies as they are committed to continuing medical education and providing the best practices in patient care.

For further information about ASCO and its medical and patient programs, contact www.asco.org or 703-299-0150.

Tip #1 Your Medical Team

On the East End there are many outstanding “GPs,” meaning physicians who are in general practice. A general practitioner also can be known as your “primary care physician.”

The diagnosis of cancer can begin with your GP. During an annual checkup, for example, a GP may see something of concern and order further tests which may or may not confirm that a patient has cancer.

The treatments for cancer occur under specialists – such as the many exceptional oncologists listed in the Guide. They should have good communication with a patient’s GP and, together, these doctors form the core of a cancer patient’s medical team.

ONCOLOGY

Your oncologist will most likely be the central person on your medical team, helping coordinate all aspects of your treatment with other practitioners. The oncologist will often treat cancer by administering chemotherapy. Many physicians employ nurse practitioners who also can assist you with your treatment issues. Below you will find a listing of oncology practices as well as individual oncologists in your area.

Barry L. Strauss, M.D.

353 Meeting House Lane 631-283-6611
Southampton, NY 11968

Eastern Long Island Hematology/Oncology

Dr. Louis Avvento & Dr. Alexander Zuhoski..... 325 Meeting House Ln.
1333 East Main St..... Southampton, NY 11968
Riverhead, NY 11901..... 631-727-8500
Southampton 631-204-9700
..... www.eliho.com

North Shore Hematology Oncology Associates

285 Sills Road, Building 16
Patchogue, NY 11772 631-758-7575
887 Old Country Road
Riverhead, NY 11901..... 631-727-3215
For a complete physician directory visit..... www.nshoa.com

Patchogue Medical Oncology

Dr. Stanley Ostrow
285 Sills Road, Building 16, Suite D..... 631-758-7575
Patchogue, NY 11772

Chapter Two: **Doctors**

Peconic Regional Hematology Oncology

Dr. Marilyn McLaughlin

36 Osprey Avenue 54075 Main Road
Riverhead, NY 11901 Southold, NY 11971
631-727-3000 631-765-4600

St. Catherine of Siena Medical Center

50 Route 25A, Smithtown, NY 11781 631-862-3000

Stony Brook University Hospital, The Cancer Center

3 Edmund Pellegrino Road

Stony Brook, NY 11794 631-638-1000

www.stonybrookmedicalcenter.org

Twin Forks Hematology Oncology, P.C.

Dr. Susan Emanuele 201 Manor Place
Mon., Tues., Fri. Weds. 8am-4:30pm
1267 East Main Street Eastern LI Hospital
Riverhead, NY 11901 Greenport, NY 11944
631-727-7100 631-477-0025

RADIATION THERAPY

Radiation therapy or radiotherapy uses ionizing radiation as a “bladeless knife” to destroy active cancer cells in the body. The goal of radiation is to kill cancer cells without harming the healthy tissue. Below, you will find a listing of radiation therapy practices.

North Fork Radiology & Radiation Oncology

Dr. Renu Hausen

1333 Roanoke Avenue – Suite 102 631-727-2755 ext.400
Riverhead, NY 11901 631-727-2877 Fax

Patchogue Radiation Therapy Center

285 Sills Road, Building 17

Patchogue, NY 11772 631-207-2801

Radiation Oncology

181 North Belle Mead Road

East Setauket, NY 11733 631-689-6776

Stony Brook University Hospital

Nicolls Road and Health Sciences Drive Intersection

Stony Brook, NY 11794 631-444-2200

Tip #2 Planning for Radiation

Radiation is a time-consuming process; treatments typically last for six weeks, five days a week. There are not many radiation treatment centers on the East End – so think about transportation. It can be helpful if friends and family share the many days of driving.

If the cancer patient is working, it is also prudent to consider a reduced or altered work schedule during the period of radiation treatments.

For more information about the practice of oncology, please visit the following websites.

American Cancer Society

Information, referrals, resources, guidance and educational material.

www.cancer.org 800-ACS-2345

Cancer.net

The American Society of Clinical Oncologists patient website.

www.cancer.net 888-651-3038

National Comprehensive Cancer Network

Treatment guidelines for patients, listing of national cancer centers.

www.nccn.org 888-909-6226

National Cancer Institute, Cancer Information Service

Accurate, up-to-date medical information.

www.cancer.gov 800-4-CANCER

TIP #3 NCCN Treatment Guidelines www.nccn.org

“NCCN” stands for National Comprehensive Cancer Network. It is a not-for-profit alliance of 21 of the world’s leading hospitals.

Recently, the NCCN and the American Cancer Society have teamed up to publish a simplified version of NCCN guidelines. Each pamphlet covers a different type of cancer. Available through the Fighting Chance Library. Also available in Spanish.

Successful Communication with your Doctor and Healthcare Team: A Two-Way Street.

As a cancer patient, you need a doctor who offers and interprets medical information, who coordinates your care, and with whom you can speak frankly. Today's medical care is complex and technical. Communicating with a team of specialists including surgeons, radiologists and nurses offers you the benefit of their shared views and is important at all stages of cancer treatment and survival.

Tips/Suggestions for Effective Communication:

- Bring a family member or friend. This may help with asserting yourself and later review in the new information conveyed.
- Tape important discussions. Absorb information by listening to the tape at home when there is less stress. Be sure to get your doctor's permission before recording him /her.
- Understand your treatment plan before you leave the office. Ask the doctor to clarify all information. What tests/medicines have been prescribed; how long will you be taking them; what are the risks and benefits of your treatment.
- Speak clearly and openly with your doctor/healthcare team. Describe and relate all symptoms, observations and concerns. Remember, doctors cannot read your mind.
- Let your doctor know how much information you need to know or can tolerate. While there is much information to understand about all aspects of your condition, only you know if you feel overwhelmed or overloaded with statistics and information. It is important to let the doctor know if the information is too frightening. If you would like more information on your treatment, let the doctor and healthcare team know. Also, let your healthcare team know if you do not understand a particular medical term.

Finally, remember that physicians, nurses, and technicians are medical professionals who are committed to serve you. Try to be pleasant, courteous and appreciative. Understand that time is at a premium in today's medical environment. However, if you feel constantly hurried, or are not treated with respect or your questions are not being addressed, bring this up with your doctor. If all else fails, consider looking for another physician.



SECOND OPINIONS

Even after you have selected your doctor or medical team it may be important to get a second opinion. Volumes of new information on the latest cancer developments are produced every day. Your doctor may not be aware of all of them. Checking in with another expert gives you the opportunity to validate your doctor's diagnosis and recommended treatment approach or to identify a new perspective with new options and alternatives that you may not have known were available.

Challenge: I'm interested in getting a second opinion. What steps should I take?

Solution: Obtaining a second opinion is a common practice, so your doctor should be very comfortable with the request. Your doctor should provide the referral doctor with all of your medical records and any other pertinent information he/she might need to evaluate your situation.

In most cases, it is up to the patient to retrieve their medical records from their referring physicians. Do not be afraid to ask for this information; it is, after all, your medical information.

Remember to read your insurance policy and check to confirm that a second opinion will be covered. In some cases your insurance company may require a second opinion and may require that you see someone in its network.

Get a second opinion when:

- You want to be sure you have explored all options.
- You think there may be another treatment available.
- Your insurance plan requires it.

TIP #4 What is a “Comprehensive Cancer Center”?

The National Cancer Institute or NCI spends billions of dollars each year on cancer research. Some of the largest grants go to medical facilities that the NCI designates as Comprehensive Cancer Centers or CCCs. There are 39 of them in the U.S. and they are noted for combining high quality clinical care with superb academic research.

There are four CCCs in New York State and two of them are in New York City. One is Memorial Sloan-Kettering Cancer Center (212-639-2000) and the other is the Herbert Irving Comprehensive Cancer Center of Columbia University (212-305-5201).

Due to their deep roots in cancer research, CCC's tend to be excellent places to go for second opinions or to learn about the latest clinical trials.

Finding the Best Doctor for a Second Opinion

Many cancer patients seek second opinions to confirm their diagnosis and treatment plan. Usually, a second opinion will probably not provide an entirely different diagnosis – for example, concluding that there is no cancer present. Instead, most second opinions tend to focus on different treatment options, some of which are “cutting edge” and occasionally the subject of clinical trials.

From this perspective, the “best” doctor for a second opinion probably will have a scholarly bent and will be affiliated with a research-oriented hospital such as a CCC. Of the 39 CCCs in this country, there are some facilities that are also members of the National Comprehensive Cancer Network or NCCN. The NCCN institutions are often portrayed as the “Cadillacs” of cancer care hospitals.

A sensible criterion for picking a second opinion doctor would be to identify a doctor who is on the medical staff or faculty of a CCC institution which is also a member of the NCCN. Within the East Coast area, four institutions meet that definition: Memorial Sloan-Kettering Cancer Center in New York City (212-639-2000); Dana Farber Cancer Institute in Boston (617-632-4266); Rosewell Park Cancer Institute in Buffalo (716- 845-5772); and the Kimmel Comprehensive Cancer Center at Johns Hopkins in Baltimore (410-955-8964).

You can find a list of CCCs on the NCI’s website (www.cancer.gov) and the NCCN’s website (www.nccn.org) which lets you pick a doctor by specialty. It will provide background information on his/her field of work plus a phone number.

Working with your Local Hospital on Arrangements for a Second Opinion.

Many cancer patients who originally were being treated at a hospital on the East End of Long Island seek a second opinion from a major Comprehensive Cancer Center.

Cancer patients should realize that it can take several weeks to get a doctor's appointment for a second opinion. And, before the appointment, the doctor needs to receive information already acquired, which typically includes (1) biopsy pathology slides and reports; (2) radiology files and reports, such as x-rays and CT scans; and (3) any other relevant physician reports.

If chemotherapy or radiation therapy has already started, then summaries of treatments to date are necessary. Some cancer centers will not see you if you are currently undergoing treatment.

The staffs at local hospitals tend to be very cooperative, but the cancer patient or caregiver still has a lot of material to organize in connection with seeking a second opinion. Be your own best advocate!

Tip #5 The Option of Memorial Sloan-Kettering Cancer Center

Memorial Sloan-Kettering is the largest hospital facility in America dedicated exclusively to cancer, i.e., diagnosing cancer; treating and curing cancer and undertaking clinical trials and other research to find the causes (and sometimes the cure) for many types of cancer. It is an extraordinary resource.

“Memorial” (as the hospital is commonly known) has several facilities in Manhattan as well as new “satellite” offices on Long Island. See Tip # 6 on page 23.

The fact that the Memorial facilities are accessible expands the medical options for cancer patients on the East End. Understanding the full range of medical options is an important “life skill” for cancer patients and their caregivers.







HOSPITALS & HEALTHCARE CENTERS

Getting diagnosed with cancer means spending a lot of time at a hospital or healthcare center for testing, treatment and check-ups.

Challenge: How do I find the best hospital/healthcare center for me?

Solution: Hospitals and healthcare centers are institutions that provide medical and surgical care for the sick and injured. However, not all hospitals and healthcare centers are the same. Learning about an institution’s philosophy, its strengths, its weaknesses, the number and kinds of doctors associated with it, can help you select a hospital/healthcare center that is most consistent with your needs.

Below you will find a listing of hospitals and healthcare centers and their websites.

Brookhaven Memorial Hospital Medical Center

101 Hospital Road
 East Patchogue, NY 11772..... 631-654-7100
www.brookhavenhospital.org

East End Pain Center

Center for the Diagnosis & Treatment of Acute, Chronic & Cancer Pain
 365 County Road 39A, Suites 16
 Southampton, NY 11968..... 631-702-2300
www.eastendpain.com

East Hampton Healthcare Center

200 Pantigo Place
 East Hampton, NY 11937 631-324-8434
www.easthamptonhealthcare.org

East Hampton Urgent Care

470 Montauk Highway
 East Hampton, NY 11937 631-329-5900

Chapter Four: **Hospitals & Healthcare Clinics**

Eastern Long Island Hospital

201 Manor Place
Greenport, NY 11944 631-477-1000
www.elih.org

Hampton Community Health Care

1152 Montauk Highway
Water Mill, NY 11976 631-726-8033

Hampton Medical Atrium

182 West Montauk Highway
Hampton Bays, NY 11946 631-723-7013

Memorial Sloan-Kettering Cancer Center of Commack

650 Commack Road
Commack, NY 11725 631-623-4000
www.mskcc.org

Peconic Bay Medical Center (formerly Central Suffolk Hospital)

1300 Roanoke Avenue
Riverhead, NY 11901 631-548-6000
www.peconicbaymedicalcenter.org

Southampton Hospital

240 Meeting House Lane
Southampton, NY 11968 631-726-8200
www.southamptonhospital.org

University Hospital at Stony Brook

Nicolls Road
Stony Brook, NY 11794 631-689-8333
www.stonybrookmedicalcenter.org

Wainscott Walk-In Medical Care

Montauk Hwy & 83 Wainscott Northwest Road
Wainscott, NY 11975 631-537-1892

Cancer Surgery on the East End

There are several surgeons who are treating colon, pancreatic, breast, kidney, skin and prostate cancers on both the North and South Fork.

Breast Surgery

Patricia A. Farrelly, M.D., Louis T. Merriam, M.D.

Stony Brook Outpatient Services

225 West Montauk Highway

Hampton Bays, NY 11946 631-723-5000

Edna Kapenhas-Valdes, M.D.

Southampton Hospital's Ellen Hermanson Breast Health Center

234 Hampton Road

Southampton, NY 11968..... 631-287-1433

Colorectal Surgery

Martyn W. Burk, M.D.

Stony Brook Technology Park

37 Research Way

East Setauket, NY 11733 631-444-4545

Marvin L. Corman, M.D.

Stony Brook University Cancer Center

3 Edmund D. Pellegrino Road

Stony Brook, NY 11794..... 631-638-1000

Dermatologic Surgery

Evan Jones, M.D.

Stony Brook Dermatology Associates

181 North Belle Mead Road, Suite 6

East Setauket, NY 11733 631-444-4200

Ashfaq A. Marghoob, M.D.

Memorial Sloan-Kettering Skin Cancer Center

800 Veterans Memorial Highway, 2nd Floor

Hauppauge, NY 11788..... 631-863-5100

Chapter Four: **Hospitals & Healthcare Clinics**

Kenneth A. Mark, M.D.
East Hampton Healthcare Center
200 Pantigo Place
East Hampton, NY 11937 631-324-4161

General Surgery

Peconic Surgical Group, P.C.
31 Main Road, Suite 2
Riverhead, NY 11901 631-369-8539
www.peconicsurgicalgroup.com

Gynecologic Surgery

Eva Chalas, M.D.
Long Island Gynecologic Oncologists, P.C.
1077 West Jericho Turnpike
Smithtown, NY 11787 631-864-5440
www.ligynonc.com

Kent C. Chan, M.D.
Stony Brook University Cancer Center
3 Edmund D. Pellegrino Road
Stony Brook, NY 11794 631-638-1000

Hannah Ortiz, M.D.
13105 Main Road
Mattituck, NY 11952 631-298-4655

Urologic Surgery

Robert A. Munkelwitz, M.D. F.A.C.S.
Southampton Hospital
117 Hampton Road
Southampton, NY 11968 631-287-8600

TIP #6 Memorial Sloan-Kettering Cancer Center “Satellites” on Long Island.

Memorial Sloan-Kettering Cancer Center or MSK has three outpatient centers on Long Island that could be an attractive alternative for East End cancer patients who cannot easily make the trip to MSK’s main facility in New York City.

The satellite in Suffolk County has 12 doctors and offers medical oncology, chemotherapy, radiation oncology, radiology, surgery consultations, genetic counseling and integrative medicine, all in a location that’s convenient for you.

650 Commack Road, Commack NY 11725.....631-623-4000

The satellite in Nassau County, located in the Mercy Medical Center, is a smaller facility. It has six doctors (three radiation oncologists and three medical oncologists) who provide outpatient chemotherapy and radiation services.

1000 North Village Avenue, Rockville Center, NY 11570

Medical Oncology516-256-3651

Radiation Oncology516-256-3600

In recent years, a Skin Cancer Center was established in Hauppauge. This facility provides dermatology services, including Mohs surgery. Used primarily to treat squamous and basal cell carcinomas, Mohs surgery allows the surgeon to pinpoint and remove cancerous tissue while leaving healthy skin intact.

800 Veterans Highway, 2nd Floor, Hauppauge, NY 11788.....631-863-5100

Doctors at all three satellites benefit from many kinds of collaboration with MSK’s main facility. This includes, perhaps most importantly, the ability to connect with the world class faculty in terms of cancer diagnosis, potential treatments and availability of clinical trials.



Tip #7 Ambulance Services on the East End

In case of a medical emergency, dial 911.

It's always a good rule of thumb to dial 911 in a medical emergency but there may be a time where a situation is not an emergency but medical assistance is still needed. Each town provides its own ambulance service that is assessible by calling your local fire department. Below you will find a listing of local fire and ambulance phone numbers.

Amagansett	631-267-3033	Bridgehampton	631-537-0336
Cutchogue	631-734-6907	East Hampton	631-324-0124
Greenport	631-477-9801	Hampton Bays	631-728-9191
Mattituck	631-298-8833	Montauk.....	631-668-5695
Quogue.....	631-653-4620	Sag Harbor.....	631-725-0252
Shelter Island	631-749-0184	Southold.....	631-765-3385
Southampton	631-283-0072		



CLINICAL TRIALS



There are new discoveries in cancer research every day. Translating scientific discoveries into improved cancer care for people requires testing through the clinical trials process. Clinical trials are research studies testing new prevention and treatment methods to determine whether they are effective and safe, and better than the best-known treatment or current standard of care. Deciding whether to participate in a clinical trial can be a very difficult decision.

As treatments are untested, the outcomes are unpredictable. That means that some people may benefit from participating and some people may expose themselves to risks. (See the section Understanding the Risks and Rewards below.) This is a highly personal choice without a right or wrong answer. Learning as much as you can about clinical trials in general is a good place to start.

Challenge: How do I know if a clinical trial is right for me?

Sollution: The only way to know if a certain clinical trial is right for you is to discuss it with your doctor. Only your doctor knows your medical history and can determine if a clinical trial is a viable treatment option.

How Clinical Trials are Set Up

All clinical trials have guidelines about who can participate. These guidelines, called eligibility criteria, describe characteristics that must be shared by all participants. Eligibility criteria for clinical trials include a person's age, gender, medical history and current health status and often require that patients have a particular type and stage of cancer.

Each trial follows a protocol or set of rules. A protocol is a kind of "action plan" for the clinical trial. The plan will describe the schedule of tests, procedures, medications and doses as well as the length of the study. Participants will receive a written consent form explaining the study. People who agree to take part in the study are asked to sign the informed consent form. However, signing the form does not mean a person must stay in the study. A participant can leave the study at any time, either before the study starts or at any time during the study or the follow-up period.

While in a clinical trial, participants are seen regularly by the research staff to monitor their health and determine the safety and effectiveness of the treatment. The research team consists of doctors, nurses, social workers and other healthcare professionals.

Phases of Clinical Trials

Phase I: Is the Treatment Safe?

While these treatments have been well-tested in the laboratory and on animals, their impact on humans at this stage is unknown. Phase I tests to see if a treatment is safe for humans and to determine the dosage of any medications.

Phase II: Does it Work?

Once a treatment is deemed safe for use by humans, the next step is to see whether the treatment works against cancer. Researchers look for a response: is the cancer affected by the treatment? If a certain percentage of patients respond favorably, the treatment is then considered effective enough to go on to Phase III.

Phase III: Is it Better Than the Current Standard Treatments?

Phase III compares the effectiveness of the new treatment against the standard treatment for a particular cancer. Even if a treatment was found to be effective in Phase II, it is important for doctors to understand how well a particular treatment performs relative to current available treatment options. This phase determines whether a new treatment is more effective (or possibly less toxic) than the current standard of care. Phase II trials usually include a small number of people, whereas Phase III trials usually enroll hundreds to thousands of participants in order to gather large amounts of data from patients of various ages, multiple ethnicities and both genders so that the results can be applied to a larger population.

Once a drug has been proven successful in a Phase III trial, the researchers can submit an application for FDA approval. If the data from clinical trials meet the FDA standards, the treatment will be approved for a specific use.

(Adapted from People Living With Cancer, an ASCO website. For more complete information go to www.cancer.net and link to clinical trials)

Finding an Appropriate Clinical Trial

Certain websites can be very efficient in finding a clinical trial. However, your doctor is the best resource for finding a clinical trial that's right for you. If you wish to search the web for clinical trials, there are several websites that might prove beneficial to you. To find trials sponsored by drug companies go to *www.centerwatch.com*. To find government-sponsored trials go to *www.cancertrialshelp.org*. Both sites let you search the cancer type and the location of the participating hospital nearest you. The NCI's website (*www.cancer.gov*) also includes a comprehensive list of trials but in technical terminology.

Who Pays for the Costs Associated with a Clinical Trial?

Health insurance and managed care providers often do not cover the patient care costs associated with a clinical trial. What is covered varies among insurance companies and for each trial. Oftentimes, the study drug itself will be free of charge but the patient is responsible for the doctor's visits as well as the follow-up tests that monitor his/her condition throughout the trial process. It may be helpful to have someone from the research team talk about coverage with a representative from your insurance company.

Understanding the Risks and Rewards

As you consider your treatment options, keep in mind some of the benefits of clinical trial participation: in general, doctors and nurses who are involved in clinical trial research are aware of the latest cancer treatment advances. Therefore, your participation can afford you access to cancer treatments that are not yet widely available. Should those treatments be particularly successful, you would be among the first to benefit. Second, those involved in clinical trials receive very close healthcare monitoring to detect and track both treatment progress and potential side effects. Third, many who participate in clinical trials derive great satisfaction from contributing to the advancement of cancer research that may benefit future cancer patients. Finally, participants in clinical trials increase their sense of empowerment as they take a more active role in their own treatment process.

Along with the rewards there are also risks to consider. With each clinical trial, especially Phase I trials, there are potential side effects, and because the treatment is new sometimes these side effects are unknown and unpredictable. There is the possibility that the new treatment or intervention is not as effective as the current treatment. Also, since everyone reacts to treatments differently, it may be that while the new intervention is more effective for others, it may not be as effective for you.

Clinical trials tend to take place in larger, urban hospitals. For most, this requires more and frequent trips to the clinic for closer healthcare monitoring. These trips may be challenging since transportation to the larger hospital centers may be difficult to arrange, some may find it difficult to obtain transportation coverage from their health insurer. Ultimately, the decision to participate in a clinical trial is highly personal. It involves careful consultation with your medical team to understand the potential risks and rewards of any particular clinical trial with respect to your situation.

(Adapted from Coping Magazine, March 2006)

For Clinical Trial Information

National Cancer Institute <i>www.cancer.gov</i>	1-800-4-CANCER
Coalition of National Cancer Cooperative Groups <i>www.cancertrialshelp.org</i>	1-877-520-4457
American Cancer Society: Clinical Trials Matching Service <i>www.cancer.org</i>	1-800-ACS-2345

TIP #8 Making Your Decision about Clinical Trials

Before you decide to take part in a clinical trial, you should know as much as possible about it. Be sure to consult with your medical team about the risks and benefits involved in your participation. Ask your medical doctor for more details on the trial such as:

- What is the purpose of the study?*
- How many people will be included in the trial?*
- What does the study involve? What kinds of tests and treatments will I have?*
- How are treatments given and what side effects should I expect?*
- What are the risks and benefits of each protocol?*
- How long will the study last? What type of long-term follow-up care is provided?*
- Will I have any costs? Will any of the treatments be free? What does my insurance cover? Is financial aid available?*



INSURANCE & FINANCIAL ASSISTANCE

When you are diagnosed with cancer, the right healthcare insurance plan can make a big difference. If you lack sufficient healthcare coverage, understanding the insurance system and where you can go for additional financial support may go a long way in reducing your concerns.

There are three “typical” ways people secure health insurance in the United States. Many employees receive health insurance benefits through their employers. Others who do not have health insurance through an employer may purchase health insurance privately. Finally, there is a system of federal and state-funded health insurance coverage.

Employee-based Health Insurance

Read your policy carefully! Every insurance company is different!

The majority of insurance companies that provide insurance through employers cover standard cancer treatments such as radiation, chemotherapy and surgery.

In order to best understand what your insurance covers, be sure to review the literature your employer and insurance company have given you describing your benefits. Compile all questions that you may have about your coverage and review them with the benefits administrator at your place of employment and a representative from your insurance company.

Please keep in mind as you compile your information that there are five federal laws dealing with your healthcare rights:

ERISA (Employment Retirement Income Security Act of 1974)

ERISA is a federal law that sets minimum standards for most voluntarily established pension and health plans in private industry to provide protection for individuals in these plans.

COBRA (Consolidated Omnibus Budget and Reconciliation Act of 1986)

COBRA gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan for limited periods of time under certain circumstances such as voluntary or involuntary job loss, reduction in the hours worked, transition between jobs, death, divorce, and other life events. Qualified individuals may be required to pay the entire premium for coverage up to 102 percent of the cost to the plan.

ADA (Americans with Disability Act of 1990)

ADA prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities.

www.ada.gov

FMLA (Family and Medical Leave Act of 1993)

FMLA is designed to help employees balance their work and family responsibilities by allowing them to take reasonable unpaid leave for certain family and medical reasons. It also seeks to accommodate the legitimate interests of employers and promote equal employment opportunity for men and women. The Family and Medical Leave Act provides certain employees with up to 12 weeks of unpaid, job-protected leave per year. It also requires that their group health benefits be maintained during the leave.

HIPPA (Health Insurance Portability and Accountability Act of 1996)

HIPPA provides rights and protections for participants and beneficiaries in group health plans. HIPAA includes protections for coverage under group health plans that limit exclusions for preexisting conditions; prohibit discrimination against employees and dependents based on their health status; and allow a special opportunity to enroll in a new plan to individuals in certain circumstances. HIPAA may also give you a right to purchase individual coverage if you have no group health plan coverage available, and have exhausted COBRA or other continuation coverage.

For more information on these programs please visit the following website:

<http://www.dol.gov/dol/topic/health-plans/index.htm>

Federally Funded Insurance Programs

Federally Funded Insurance usually falls under two main categories: Medicare and Medicaid.

Medicare

Available for people who are 65 years or older and/or those who are disabled for more than 2 years, legally blind or on renal dialysis. Co-pays and/or deductibles are required for treatments and services.

Medicare Part A

Medicare Part A helps cover your inpatient care in hospitals, critical access hospitals, and skilled nursing facilities (not custodial or long-term care). It also helps cover hospice care and some home health care. You must meet certain conditions to get these benefits.

Medicare Part B

Medicare Part B helps cover medical services like doctors' services, outpatient care, and other medical services that Part A doesn't cover. Part B is optional. Part B helps pay for covered medical services and items when they are medically necessary. Part B also covers some preventive services like exams, lab tests, and screening shots to help prevent, find, or manage a medical problem.

Medicare Advantage Plans or Part C

Medicare Advantage Plans are health plan options that are approved by Medicare but run by private companies. They are part of the Medicare Program, and sometimes called "Part C." They provide all your Part A and Part B coverage and must cover medically-necessary services. They generally offer extra benefits, and many include Part D drug coverage. You may have to see doctors who belong to the plan or go to certain hospitals to get covered services.

Medicare Part D

Medicare Part D is prescription drug coverage offered to everyone with Medicare. This coverage may help lower prescription drug costs and help protect against higher costs in the future. It can give you greater access to drugs that you can use to prevent complications of diseases and stay well. These plans are run by insurance companies and other private companies approved by Medicare. Part D is optional.

For more information visit www.medicare.gov or www.medicarerights.org.

Medicaid

Medicaid is available to low-income individuals and families who fit into an eligibility group that is recognized by federal and state law. Medicaid does not pay money to you; instead, it sends payments directly to your health care providers. Depending on your state’s rules, you may also be asked to pay a small part of the cost (co-payment) for some medical services. Basic benefits are required by the federal government, but states can add additional benefits.

Hospital care, physician visits, prescriptions and home healthcare services are provided to persons who will be disabled for more than a year.

For more information about New York State’s Medicaid Program contact:

www.health.state.ny.us/health_care/medicaid/ 1-800-541-2831

State Funded Insurance Programs

EPIC (Elderly Pharmaceutical Insurance Coverage)

EPIC is a New York State sponsored prescription plan for senior citizens who need help paying for their prescriptions. Must be age 65 or older. The cost-sharing program applies to low-to-moderate income persons. Enrollees may be eligible for reimbursement of doctor’s fees and portions of co-payments under a program funded by Suffolk County. (631-853-8200).

For more information on eligibility requirements please visit:

http://www.health.state.ny.us/health_care/epic/ 1-800-332-3742

Family Health Plus

Family Health Plus is a public health insurance program for adults between the ages of 19 and 64 who do not have health insurance - either on their own or through their employers - but have income or resources too high to qualify for Medicaid. Family Health Plus is available to single adults, couples without children, and parents with limited income who are residents of New York State and are United States citizens or fall under one of many immigration categories.

For more information please visit:

http://www.health.state.ny.us/nysdoh/fhplus/what_is_fhp.htm 1-877-934-7587

Child Health Plus:

Child Health Plus is a New York State health insurance plan for children under the age of 19 who are residents of New York State. Whether a child qualifies for Children’s Medicaid or Child Health Plus depends on gross family income. Children who are not eligible for Medicaid can enroll in Child Health Plus if they don’t already have health insurance and are not eligible for coverage under the public employees’ state health benefits plan. For more information please visit:

http://www.health.state.ny.us/nysdoh/chplus/what_is_chp.htm 1-800-698-4KIDS

Breast, Cervical, Colorectal and Prostate Cancer Treatment Program:

The Healthcare Workforce Recruitment and Retention Act expanded Medicaid eligibility to certain individuals diagnosed with breast, cervical, colorectal, and prostate cancer or pre-cancerous conditions. Individuals are now eligible for Medicaid benefits for the duration of their cancer treatment. For more information please visit:

<http://www.health.state.ny.us/nysdoh/bcctp/bcctp.htm> 1-866-442-2262

What to do when your coverage is not enough:

If you are finding that your insurance coverage is insufficient, and that your insurance company is unwilling to reimburse claims, there are several organizations and programs that will help you advocate your cause.

Health Insurance Assistance Service

Aids cancer patients who have lost or are in danger of losing their health care coverage, along with identifying policy solutions to help others in similar situations. The service, a joint effort of the ACS and the Georgetown University Health Policy Institute, connects cancer patients who call the ACS cancer information number with health insurance specialists who work to address their needs.

www.cancer.org 1-800-ACS-2345

Chapter Six: **Insurance & Financial Assistance**

Health Insurance Counseling and Assistance Program of New York

The HICAP program assists seniors with health insurance paperwork. Trained volunteers provide the elderly with information and assistance regarding claims and appeals decisions for Medicare, Medicaid, supplemental and long-term care insurance.

Call a volunteer counselor at.....631-853-8200

<http://www.hicap.state.ny.us/>

The Hill Burton Program

Provides free and reduced cost healthcare at some hospitals with federal funding to help eligible patients obtain treatments they might not be able to afford.

For a list of participating hospitals call:.....1-800-638-0742

The Patient Advocate Foundation

Employs case managers and attorneys who advocate on behalf of patients who are experiencing a range of insurance issues.

700 Thimble Shoals Blvd., Suite 200

Newport News, VA 23606 1-800-532-5274

www.patientadvocate.org

The Plan Project, Nassau/Suffolk Law Services

Provides free legal assistance to cancer patients regarding powers of attorney, healthcare proxies, health insurance coverage, Medicaid denials and numerous other legal issues that may arise. Contact Denise Snow, Esq.

1757 Veteran's Highway

Islandia, NY 11749 631-232-2400

Entitlements/Assistance

You are entitled to certain government programs known as entitlements that are supported through your tax contributions over the years.

Social Security Administration

Suffolk County Office

526 East Main Street

Riverhead, NY 11901..... 1-800-772-1213

www.ssa.gov

Supplemental Social Security 1-800-772-1213

www.ssa.gov/ssi

Additional Assistance

If you are having trouble paying for your medications, try contacting the manufacturer of the drug. Often, drug companies have financial assistance programs. If you need assistance finding the drug manufacturer or patient assistance programs, please visit www.needymeds.com. Needymeds is an information source similar to the Yellow Pages. Needymeds does not supply medications or financial assistance but will help you find programs that do.

You may also want to contact the National Council on Aging for information on drug company sponsored discount programs. The NCOA helps older people remain healthy and independent, find jobs, increase access to benefits programs, and discover meaningful ways to continue contributing to society. www.ncoa.org or www.benefitscheckup.org

If you are in a position to select a better health insurance plan to meet your needs, be sure to refer to The Association of Community Cancer Center’s (ACCC) guidelines for Minimum Standards for Cancer Benefits in Insurance Policies to ensure that your coverage will be sufficient. www.accc-cancer.org/publications/301-984-9496

If you would like to purchase your own insurance you may consider joining an association such as the National Association for the Self-Employed (NASE) to qualify for less expensive group coverage. The process of becoming a “self-employed” worker is fairly simple. Consult the NASE website or call them for more details. www.nase.org1-800-232-6273

For more information about supplemental insurance, health related news and advocacy for people age 50 and older contact;

The American Association for Retired People
AARP New York Office
780 3rd Avenue, 33rd Floor
New York, NY 100171-866-227-7442
www.aarp.org/states/ny/

Tip #9 Who Pays for the Next Test or Treatment?

Once someone is diagnosed with cancer, it is very important to try to understand the types of future tests and treatments that are covered by insurance – meaning the insurer pays the costs.

The insurer could be an HMO or the government itself (in the case of Medicaid/Medicare).

Occasionally, there may be a test or treatment that is “cutting edge” and promising – but is very expensive and beyond the scope of the cancer patient’s insurance policy.

In essence, the test or treatment becomes “unaffordable.” At times like that, our healthcare system can seem imperfect.

On the other hand, many Americans are covered by some type of healthcare insurance. And most insurance policies certainly pay for basic cancer therapies such as chemotherapy and radiation.



COMPLEMENTARY & ALTERNATIVE MEDICINE

A cancer diagnosis may send some people seeking answers in the direction of non-standard treatment. Standard treatments are those that have been scientifically tested, found to be safe and effective and approved by the U.S. Food and Drug Administration. Non-standard approaches to treatment, referred to as complementary and alternative medicine, are those treatments that have not undergone the same type of rigorous safety and efficacy testing, and have not been evaluated in structured unbiased clinical trials. Usually, healthcare practitioners refer to any form of therapy used in combination with other alternative treatments or standard medicine as complementary. Those therapies that are used alone, in place of the recommended standard treatments, are considered alternative.

Complementary medicine can be an important element in your cancer care. Research has shown that some complementary therapies may help ease side effects of traditional treatments and promote healing in the mind and body. Other alternative therapies may be potentially harmful due to unknown drug/herb interactions. Be sure to discuss the advantages or contraindications for use of alternative medicines with your oncologist and health care team.

Challenge: Where can I find additional sources of healing support in my community?

Solution: There are a number of complementary health practitioners on the East End who represent a wide range of philosophies, practices and services. Below you will find a list of basic definitions for some complementary medicine practices as well as a list of practitioners. Remember, as with any health practitioner, be selective!

Acupuncture is a traditional Chinese therapeutic technique wherein the body is pierced with fine needles to promote healing and provide pain relief.

Massage Therapy is a “hands-on” form of medical treatment, based on an in-depth understanding of musculoskeletal, circulatory, lymphatic and nervous systems of the body. The goal of massage therapy is to increase mobility and reduce swelling, pain and scar tissue formation.

Manual Lymphatic Drainage Removal of the lymph nodes is a common intervention to diagnose and prevent the spread of cancer. Often this surgery can cause lymphedema or swelling due to congestion in the lymphatic pathways. Manual lymphatic drainage (MLD) is a massage therapy technique that aims to activate and to regularize the circulation of the lymphatic system and reduce the pain and swelling associated with some cancer treatments.

Reiki is a traditional Japanese healing technique that focuses on tapping into “life force energy.” It aims to improve emotional, spiritual and physical well-being through stress reduction and relaxation.

Transformational Breath Work is a breathing technique used for therapeutic purposes in order to release blocked energy from the physical, mental and spiritual self and promote healing on all levels.

Yoga is a series of exercises intended to make the body strong and flexible, it also improves the functioning of the respiratory, circulatory, digestive, and hormonal systems. Yoga brings about emotional stability and clarity of mind.

Acupuncture

Mary Beth Armstrong
Main Street, Sag Harbor, NY 11963 631-725-8131

Julie Siegler-Baum
East End Accupuncture Association
200 Pantigo Place
East Hampton, NY 11937 631-329-5292

Michelle Iona, L.Ac
Peconic Family Medicine
33 Montauk Highway
Quogue, NY 11959 631-653-6000
Direct: 631-653-5314

Betina Schuler, M.S., L.Ac
acuwoman23@yahoo.com 631-255-9225
www.oceanhealingarts.com

Massage Therapy

Cindy Grant B.S, L.M.T.
Southampton Hospital, Department of Massage Therapy
240 Meeting House Lane
Southampton, NY 11968631-726-8574
Oncological Massage, Manual Lymphatic Drainage

Saundra Perry, P.T., C.L.T.-L.A.N.A
Saundra Perry Physical Therapy
57190 Main Road
Southold, NY 11971.....631-765-3620
Manual Lymphatic Drainage

Kathleen Tilley, L.M.T., C.L.T., RM/T
Peconic Family Medicine
33 Montauk Highway*sperryrehab@hotmail.com*
Quogue, NY 11959 631-653-6000
Licensed Massage Therapist and Certified Lymphedema Therapist

Integrative Medicine at Memorial Sloan-Kettering at Hauppague
800 Veterans Memorial Highway
Hauppague, NY 11788..... 631-863-5150

Nutritionists

Donald Garrity, R.D., C.D.N.
Memorial Sloan-Kettering Cancer Center
1429 First Avenue,
New York, NY212-639-4700

Paula Montagna, Dietician, M.S., R.D., C.D.N.
*Provides consults and nutrition
counseling for cancer patients, survivors and caregivers*
Peconic Family Medicine *ppmrd@optonline.net*
Quogue, NY 11955631-833-6404

Nutrition For Wellness Foundation

Aims to educate the community about the healthful benefits attained through proper nutrition.

65 Dunemere Lane
East Hampton, NY 11937 631-329-2590
www.nutritionforwellness.org

Yoga

Ananda Yoga Center

Mary Angela Buffo

Group and private classes that are appropriate and specifically for cancer patients.

20 Hampton Road
Southampton, NY 11968 631-204-1219
www.anadayogawellness.com

Mandala Yoga

Jolie Parcher, Director

156 Main Street

Amagansett, NY 11930 631-267-6144
www.mandalayoga.com

One Ocean Yoga Center

264 Butter Lane

Bridgehampton, NY 11932 631-537-5522
www.oneoceanyoga.com

Yoga Shanti Yoga Center

23 Washington Street

Sag Harbor, NY 11963 631-725-6424
www.yogashanti.com



Practitioners Providing Multiple Services

Alison M.Caiola, C.HT.

Provides imagery and visualization to help with stress management, pain management, smoking cessation, bereavement issues and overall well-being/adjustment

Riverhead, NY 11901.....631-779-3333
www.hypnosishealthcds.com

Sharmila J. Cohen-Gold, L.M.T.,

Gentle & Restorative Yoga, Reflexology, Aromatherapy, Therapeutic Massage.

Sag Harbor, NY 11963.....631-725-4995

Lisa Cowely, D.C.

Wholistic chiropractic care and nutritional counseling

44600 County Road 48

Southold, NY 11971.....631-765-1216

Pat Jeski

Certified Healing Touch Pracitioner, Crainosacral Therapy

Southampton, NY 11968.....631-727-4156

pathealingtouch@optonline.net

Lauren Matzen, L.Ac

Acupuncture/ Reiki. Works with patients on improving their immune system, coping with stress, increasing energy, and offers advice on supplements.

Southampton, NY 11968.....631-287-1465

Charyl Ozkaya

Transformational Breath, Reiki, Massage Therapy.

Hampton Bays, NY 11946.....631-723-0029

Pamela Reid, L.M.T.

Classic western/eastern massage, accupressure, heat, cryotherapy, assessment of tissue qualities, postural patterns, and energy balancing.

Sag Harbor, NY 11963.....631-725-0199

www.wholisticmassage.com

Linda Statum, Certified Hypnotherapist

Hamptons Hypnosis - Relaxation & Meditation

linda@hamptonshypnosis.com

Sag Harbor, NY 11963.....631-725-3510

www.hamptonshypnosis.com





EMOTIONAL HEALTH & CANCER

A cancer diagnosis can be an overwhelming experience. Your feelings can change daily and may include denial, fear, sadness, depression, anxiety, guilt and stress. For some, feeling more vulnerable about treatment and what the future may hold, can understandably evoke strong emotions. Although these feelings may be a normal part of having cancer, educating yourself about your illness, identifying useful coping strategies, and finding support are just some of the ways you can manage your emotions and feel more in control.

A recent report from the Institute of Medicine proposes a new standard of cancer care that integrates social and psychological support as a “routine” part of medical care for cancer patients. The report recommends that all oncology providers assess patients for signs of “distress” from diagnosis through treatment, with appropriate referrals for psychosocial care. There is strong evidence that support and interventions help with treatment compliance and reduce levels of distress for the patient and family.

Organizations such as Fighting Chance, the South Fork Breast Health Coalition and Cancer Care to name a few, are in a unique position to work with your medical healthcare providers to assist with your concerns at every juncture of your cancer experience. It is important to let your oncologist and healthcare team know of your concerns. They are treating the “whole person” and can direct you to find psychosocial support, complementary medicine practitioners, or pastoral counselors.

Self-Assessment of Distress

The American Cancer Society’s Distress booklet describes distress as “unpleasant feelings or emotions that may interfere with your ability to cope with cancer, its physical symptoms and its treatment”. The ACS questionnaire on the following page may help you sort out your concerns and issues to better determine if you might benefit from professional guidance, complementary medicine techniques, or other services.

Do I Need Professional Support?
Self-Assessment Questionnaire for Patients

The following questionnaire may help you determine whether you might benefit from professional counseling. Every patient experiences some of these symptoms; there are no right or wrong answers.

During the past two weeks:

1. I have felt anxious or worried about cancer and the treatment I am receiving.

Not at all 1 2 3 4 5 All the time

2. I have felt depressed or discouraged.

Not at all 1 2 3 4 5 All the time

3. I have been irritable or unusually angry and I have not controlled it well.

Not at all 1 2 3 4 5 All the time

4. My sleeping habits have changed.

Not at all 1 2 3 4 5 All the time

5. I have experienced a change in my appetite.

Not at all 1 2 3 4 5 All the time

6. I have had difficulty concentrating at work or at home, or on routine things such as reading the newspaper or watching television.

Not at all 1 2 3 4 5 All the time

7. Cancer and its treatment have interfered with my daily activities.

Not at all 1 2 3 4 5 All the time

8. Cancer and its treatment have interfered with my family or social life.

Not at all 1 2 3 4 5 All the time

9. Cancer and its treatment have interfered with my sex life.

Not at all 1 2 3 4 5 All the time

10. Pain and discomfort have caused me to limit my activities.

Not at all 1 2 3 4 5 All the time

11. Cancer has caused physical, emotional, or financial hardships for me.						
Not at all	1	2	3	4	5	All the time
12. Cancer and its treatment have caused changes in my physical appearance and this concerns me.						
Not at all	1	2	3	4	5	All the time
13. I have had difficulty coping with the stress I have experienced.						
Not at all	1	2	3	4	5	All the time
14. My quality of life during the past two weeks has been:						
Excellent	1	2	3	4	5	Very poor
<p>If you find that many of your answers are in column four or five, you may be experiencing significant distress and should consider discussing your feelings with a counselor.</p> <hr/> <p>Source: Developed by the Department of Psychosocial Resources, Tom Baker Cancer Centre, Calgary, Alberta, Canada. Derived in part from the Functional Living Index: Cancer and from the EORTC Core Quality of Life Questionnaire. www.cancer.org</p>						

Counseling

Finding a safe place to talk about emotional issues can be beneficial and aid adjustment. Below you will find a listing of counselors in the area.

Fran Donovan, L.C.S.W.
 P.O. Box 1574
 East Hampton, NY 11937 631-329-1314

Fighting Chance
 Karrie Robinson, L.C.S.W.-R
 William Di Scipio, Ph.D.,
 Margaret Bromberg, L.C.S.W.-R
 34 Bay Street, Suite 201
 Sag Harbor, NY 11963 631-725-4646

Chapter Eight: **Emotional Health & Cancer**

Family Counseling Center <i>Accepts most insurance-sliding fee scale</i> Central Suffolk Hospital 1300 Roanoke Avenue Riverhead, NY 11901	631-288-1954
Margaret Fox, L.C.S.W. 955 Albo Drive Laurel, NY 11948	631-298-8034
Susan Griffin, L.C.S.W. P.O. Box 1551 Sag Harbor, NY 11963	631-725-2978
Hamptons Counseling Center Jean Binnie, DAPA, M.S., M.A 143 Montauk Highway Hampton Bays, NY 11946	631-723-0648
<i>Sliding pay scale (Initial consultation is free)</i>	
Robert Kuisis, Ph.D	631-907-0539
Karen Melnick, A.S.C.W., L.C.S.W., B.C.D., C.I.S.M., <i>Family Therapy</i> East Hampton, NY 11937	631-324-0714
Mental Health Association <i>(Spanish speaking personnel)</i> Free referrals for therapists 199 North Wellwood Ave. Lindenhurst, NY 11757	631-226-3900
Edyle O'Brien, L.C.S.W. East Hampton, NY 11937	631-329-0520
Riverhead Mental Health Center 300 Center Drive Riverhead, NY 11901	631-852-1440

Coping Tips

Today, the advances in cancer diagnosis, treatments and research have increased the chances for cure or long term remission. With this good news comes the reality of increased complexities and responsibilities that patients and caregivers face along the journey. It is our goal to provide you with the practical information, guidance and strategies to ease your adjustment and help you feel more empowered.

Fighting Chance provides telephone outreach, education, navigation and support, as well as individual, family and group counseling. Assistance with employment or insurance concerns is available as well. To utilize these services please call 631-725-4646.

Cancer and Depression

Cancer is a series of crises from diagnosis, to treatment and beyond. It brings with it a great need to attend to our physical health while often experiencing overwhelming emotions that can leave us feeling as though our world has been turned upside down. Cancer takes away the illusion that we have control over our lives. Often the greater our need for control, the greater our sense of loss during cancer, leaving us more vulnerable to feelings of depression.

In general, patients with cancer are no more depressed than other patients. Yet, it is normal for periods of depression to occur at various stages of the cancer experience in response to diagnosis and treatments. For a great majority of cancer patients, a depressive reaction will subside within a week or two of its onset. Depression of this temporary form can be managed with education, active involvement in treatment, and support.

What is a depressive reaction?

A depressive reaction can include the following symptoms:

- Feeling sad, empty, hopeless, or worthless.
- Diminished interest or lessened pleasure in most activities.
- Fatigue or loss of energy, loss of appetite or overeating.
- Sleeping too much or sleeping too little.
- Thoughts of death or suicide.

When depression is more serious (where symptoms continue for more than two weeks), it is important to consult your healthcare team. Depression is manageable with medication and supportive counseling.

Strategies

- Remember that while your feelings of sadness and emptiness are unpleasant they are NORMAL. You may find that you experience them at different times during your cancer experience.
- Find ways to become an active participant in your treatment; make lists of questions for your medical team; become informed about your diagnosis and treatment options.
- Identify ways to manage your environment; make proactive choices about your diet and exercise, select the days and times (to the degree possible) you will receive your treatment, bring items (music, books, movies, people) to treatment that are soothing.
- Have compassion and patience with yourself. Give yourself permission to have your feelings.
- Engage in activities that bring you pleasure. Many people find that massage therapy, yoga, meditation, exercise, prayer, writing and art, are helpful distractions from “thinking cancer” constantly.
- If your feelings persist for longer than two weeks, consult your healthcare team to discuss whether medication and a referral for supportive counseling might be appropriate.

Here are some additional resources you may find helpful:

- National Cancer Institute - Cancer and Depression: <http://www.cancer.gov/cancertopics/pdq/supportivecare/depression/patient>
- National Institute of Mental Health: Cancer and Depression: <http://www.nimh.nih.gov/publicat/depression.cfm>
- Cancerbackup: <http://www.cancerbackup.org.uk/Resourcesupport/Relationshipscommunication/Emotionaleffects>
- American Cancer Society: http://www.cancer.org/docroot/MBC/content/MBC_4_1X_Cancer_and_Depression.asp?sitearea=MBC



PHARMACIES

Cancer drugs will be administered in the hospital, at the doctor’s office or at home, but will be prescribed for you by your doctor through a pharmacy.

Challenge: How do I select a pharmacy that is convenient, that will help reduce my confusion and keep my costs to a minimum?

Solution: It is important that you or your family members feel comfortable with the pharmacy and service you receive. Here are some helpful questions to think about as you select a pharmacy:

- Is this pharmacy in a convenient location for me or my loved ones?
- Can I have my doctor call in prescriptions to save time?
- Is the pharmacist available to answer my questions?
- Does this pharmacy accept my insurance?
- Does this pharmacy deliver?

Bridgehampton

Bridgehampton Pharmacy

2450 Main Street..... 631-537-8884

Rite Aid

200 Bridgehampton Commons..... 631-537-0235

East Hampton

CVS Pharmacy

Accepts all major insurance, spanish-speaking personnel

38 Pantigo Road..... 631-324-8587

East Hampton Pharmacy

106 North Main Street 631-324-3887

Park Place Chemists

East Hampton Healthcare Center

200 Pantigo Place, Suite K..... 631-324-6660

Chapter Nine: **Pharmacies**

White's Pharmacy
81 Main Street.....631-324-0082

Greenport

Colonial Drugs & Surgicals
100 Front Street.....631-477-1111

Hampton Bays

Center Island Pharmacy
254 West Montauk Highway.....631-728-3300

Eckerd Drugs
22 East Montauk Highway.....631-728-2566

Mattituck

Barker's Pharmacy
195 Love Lane631-298-8666

CVS
9870 Main Road.....631-298-8280

Montauk

White's Pharmacy
The Plaza.....631-668-2994

Tip #10 Natural Provisions and Herbal Medicine

Another distinctive resource on the East End is the abundance of stores that sell “natural” foods and herbal remedies. A good example is “Provisions,” located on Main Street in Sag Harbor. Most of the people who work in these stores have knowledge of what herbs can (and cannot) do. Tapping into this knowledge is a useful life skill for cancer patients – and can reveal a new range of medicinal options.

The effectiveness of herbs in fighting cancer still has many skeptics, but some respectable authorities would say that carefully selected herbs can relieve some of the symptoms that come with cancer and can enhance a patient's quality of life. Be sure to check with your oncologist before taking any herbs or supplements, as some may affect your treatment.

To check out the suitability of herbs as well as issues regarding drug interactions, please call The Integrative Medicine Service at Memorial Sloan-Kettering Cancer Center at 212-639-4700 or visit the website www.mskcc.org/aboutherbs.

Riverhead*Barth's Drug Store*

32 East Main Street 631-727-2125

CVS

1140 Old County Road 631-727-9000

Sag Harbor*Sag Harbor Pharmacy*

120 Main Street..... 631-725-0047

Shelter Island*Shelter Island Heights Pharmacy*

Grand Avenue 631-749-0445

Southampton*Corwith Pharmacy*

(Will deliver within Southampton village; Spanish-speaking personnel)

56 Hampton Road 631-283-0001

CVS

111 Main Street 631-283-4250

Rite Aid (Spanish-speaking personnel)

82 Nugent Street 631-283-2604

Southrifty Drug

54 Jagger Lane 631-283-1506

Southold*Southold Pharmacy*

53895 Main Road..... 631-765-3434

Westhampton Beach*Barth's Pharmacy Inc.*

58 Sunset Avenue 631-288-4345

Rite Aid Pharmacy

161 Main Street..... 631-288-5845

Notes:





DIETARY RECOMMENDATIONS

Basic Diet Recommendations:

- Whole grains instead of refined. (e.g., brown rice over white rice, whole wheat over white bread, etc.)
- 2-4 servings of fruit
- 3-5 servings of vegetable (depth of color and variety)
- Skim or 1 % dairy
- Legumes, fish, turkey, chicken, nuts, seeds, eggs
- Olive oil, sesame oil, canola oil, (cooking and salads), walnut oil (salads only).
- Water, White tea, Green tea, Black tea, coffee?

Recommended Readings:

American Institute for Cancer Research 1-800-843-8114

1. Recommendations for Cancer Prevention
 2. Guidelines for Cancer Prevention
 3. Eating Smart for Cancer Prevention
 4. Taking a closer look at antioxidants
 5. Taking a closer look at phytochemicals
- Many others to choose from

Websites:

Memorial Sloan-Kettering Cancer Center Integrative Medicine Center
www.mskcc.org/laboutherbs

University of Sydney
www.glycemicindex.com

Notes:





PHYSICAL THERAPY

Physical therapy is a form of rehabilitative medicine that is used for a wide range of ailments from recovery from an auto accident to increasing strength and mobility after a sports injury. Those coping with cancer may benefit from physical therapy and rehabilitation after surgery. Physical therapy can often strengthen muscles for patients confined to bed for long periods of time. Below you will find a listing of physical therapists in your area.

Eastern Long Island Hospital Physical Therapy & Fitness

46520 North Road
Southold, NY 11971..... 631-765-9389

Eileen M. Grubb, MS PT

NYS Licensed Physical Therapist
Personalized physical therapy services provided in the privacy of your own home.
emgrubbpt@gmail.com 631-324-5128
Voicemail 516-383-5609

Hampton Physical Therapy

Hampton Atrium Condominium, Suite E4
188 Montauk Hwy.
Hampton Bays, NY 11946 631-728-6377

Manual Sports Physical Therapy

Accepts all major insurance
167 Main Street
Southampton, NY 11968..... 631-283-4190
60 Bay Street
Sag Harbor, NY 11963 631-725-4450

Peconic Bay Physical Therapy & Rehabilitation Center

(Spanish-speaking personnel)

Medicare, Medicaid and all major insurance accepted

34 Commerce Drive, Suite 3

Riverhead, NY 11901631-727-9654

Personalized Hands On Care

Most insurance plans accepted

128 Sag Harbor Turnpike

Bridgehampton, NY 11932631-537-7850

Sandra J. Perry Physical Therapy

57190 Main Road

Southold, NY 11971631-765-3620

Sports Rehabilitation Network

Comprehensive Rehabilitation Services

Affiliated with Eastern Long Island and Southampton Hospitals

Accepts all major insurance, Medicaid and Medicare

240 Meeting House Lane

Southampton, NY 11968 631-726-8520

Southampton Hospital Center for Physical Therapy and Sports Rehabilitation

74 Old Riverhead Road

Westhampton Beach, NY 11978631-288-7767

Provides medical massage therapy

St. Charles Hospital & Rehabilitation Center

806 East Main Street

Riverhead, NY 11901631-369-4440





TRANSPORTATION

Coping with cancer means coping with numerous, ongoing doctor appointments. Being able to get around is vital. Transportation services are available through private car services or taxis, volunteer transportation services (sometimes run by local religious groups or agencies) or low-cost van services run by community agencies. There are some local town-sponsored programs. Check with your town or village for schedules.

Challenge: How can I find the transportation I need to get to and from all of my doctor’s appointments?

Solution: The first step in planning your transportation needs is assessing your resources. Your transportation options will typically fall into one of three categories: self/community, public and private. Tailoring a transportation plan to your needs may involve drawing on a combination of all three. Below you will find a description of these categories and a listing of specific transportation resources in your area.

Self/Community Transportation:

Road to Recovery/Transportation 1-800-227-2345
American Cancer Society offers volunteers to drive ambulatory patients to chemotherapy and radiation. ACS also provides taxi assistance and financial assistance by a Transportation Coordinator. Support available in Spanish and other languages.

If you have access to a car, you may choose to drive yourself to and from appointments. You may also create a network of volunteer drivers among your family and friends to pitch in for driving duty.

Public Transportation:

Public Transportation on the East End Bus System or through the Senior Citizen Shuttle Services is an inexpensive option for getting around.

Suffolk County Transit Service.....631-852-5200
For specific bus schedule information, call for assistance, refer to bus schedules on www.sct-bus.org or pick up a bus schedule at your village or town hall.

Chapter Twelve: **Transportation**

Suffolk County Accessible Transportation

Provides curb-to-curb service to those with permanent or temporary disabilities. Must register in advance and must be deemed eligible by calling..... 631-738-1150
<http://www.sct-bus.org/scat.html>

Southampton Town Senior Citizen Shuttle Program 631-728-1110

East Hampton Town Dept. of Human Services Senior Shuttle..... 631-324-4443

Private Transportation:

Door-to-door service is available from a number of private taxi companies on the East End.

Ace Taxi (One-day notice for appointment)

*Discounts available-Contact Fighting Chance for more information
Service from Amagansett to Westhampton to Riverhead..... 516-383-2343*

Hampton Coach Taxi

(Medicaid accepted-prior approval required)
Southampton 631-283-0242
Riverhead/Aquebogue..... 631-727-6088
East Hampton/Bridgehampton..... 631-324-7777
Greenport/Mattituck..... 631-477-2227
Westhampton..... 631-288-4044
Hampton Bays..... 631-728-0050

Hampton Jitney

*Discounts available for cancer patients by calling CancerCare, Inc.
(Schedule available online)*
www.hamptonjitney.com 631-283-4600
CancerCare, Roberta Johnson..... 516-364-8130 ext. 100

Lindy’s Ambulette Service

Provides medical transport for a fee

390 East Suffolk Avenue

Islandia, NY 11749 631-342-8888

McRides, Junior’s Taxi

(Medicaid accepted with prior approval)

Discounted rates available-contact Fighting Chance for more information

Riverhead 631-727-0707

Southampton 631-283-1900

Hampton Bays..... 631-728-5100

Westhampton Beach..... 631-288-3252

Shirley/Mastic/Moriches 631-395-1111

Transportation Matters

Paratransit, Non-Emergency Medical Transport

105 Newtown Lane

East Hampton, NY 11937 631-338-5913

Twin Forks Limo..... 631-208-1010

Tip #11 Getting to your Doctor Appointments on Time

Organizing a transportation plan is one of the most useful life skills that a cancer patient can develop. It’s similar to setting up a carpool. You puzzle out who can drive when, enlist family and friends for your team of drivers and then put together a schedule on your bulletin board.

When diagnosed with cancer, you may be surprised at the growing number of doctor appointments you have! You are seeing different types of doctors (for starters, your GP and oncologist) and may be undergoing several different tests and therapies.

Getting to all of these appointments (on time) is another “life skill” and an important way for cancer patients to help themselves, and make their doctors’ jobs easier.

Tip #12 The “Jitney”

This is a transportation “lifeline” which links the villages of the East End to New York City and runs as often as 10 times per day. Fares can change and some are adjusted for senior citizens, cancer patients and those traveling with them. Although the phone number has already been noted it will be repeated here... 631-283-4600 or 1-800-936-0400.

Long Distance Travel for Treatment

Corporate Angel Network, Inc.

*Finds free airfare transportation (on corporate planes)
for ambulatory cancer patients who need medical treatment.*

Westchester County Airport, 1 Loop Road

White Plains, NY 10604914-328-1313

www.corpangelnetwork.org

Angel Flight NE

*Finds free airfare transportation (on corporate planes)
for ambulatory cancer patients who need medical treatment.*

Lawrence Municipal Airport

492 Sutton Street

North Andover, MA 01845

Flight Requests..... 1-800-549-9980

www.angelflightne.org

Reimbursement

Helps with payments for transportation:

CancerCare of Long Island 516-364-8130

The Leukemia and Lymphoma Society 631-752-8500

South Fork Breast Health Coalition 631-726-8606

The American Cancer Society 800-227-2345

For Additional Resources please contact;

Fighting Chance

P.O. Box 1358

Sag Harbor, NY 11963 631-725-4646





SPIRITUAL SUPPORT

Many people struggling with cancer find that drawing on spiritual support can bring much strength and solace.

Challenge: Where can I go to find the right spiritual support for me?

Solution: Finding spiritual sustenance is a highly personal process and decision. Many faiths and houses of worship are represented on the East End. Finding a religious or spiritual community that meets your needs may involve attending services or meeting with the religious leader or congregants of a particular establishment. Below you will find a representative list of religious organizations on the East End.

Amagansett

- First Presbyterian Church of Amagansett631-267-6404
- St. Michael’s Lutheran Church631-267-6531
- St. Thomas Church.....631-267-3080

Bridgehampton

- Incarnation Lutheran Church ELCA-The Welcome Place.....631-537-1187
- Presbyterian Church of Bridgehampton631-537-0863
- Queen of the Most Holy Rosary Roman Catholic Church631-537-0156
- St. Ann’s Episcopal Church631-537-1527
- Unitarian Universalist Congregation of the South Fork631-537-0132

East Hampton

- Calvary Baptist Church.....631-324-5313
- First Presbyterian Church of East Hampton631-324-0711
- Jewish Center of the Hamptons631-324-9858
- Most Holy Trinity Church.....631-324-0134
- St. Luke’s Episcopal Church.....631-329-0990
- United Methodist Church631-324-4258

Greenport

First Baptist Church of Greenport.....	631-477-0047
Holy Trinity Episcopal Church	631-477-0855
St. Agnes Church	631-477-0048

Hampton Bays

Christ Our Savior Lutheran Church.....	631-728-3288
Hampton Bays Assembly of God.....	631-723-1847
Hampton Bays United Methodist Church.....	631-728-1660
St. Mary's Episcopal Church	631-728-0776

Montauk

Montauk Community Church, Presbyterian	631-668-2022
St. Therese of Lisieux	631-668-2200

Riverhead

Calvary Baptist Church of Riverhead.....	631-727-4112
Grace Episcopal Church	631-727-3900
Riverhead United Methodist Church	631-727-2327
St. Isidore Roman Catholic Church	631-727-2114
Temple Israel of Riverhead.....	631-727-3191

Sag Harbor

Conservative Synagogue of the Hamptons.....	631-725-8188
CorMaria Retreat House	631-725-4206
First Presbyterian Church of Sag Harbor.....	631-725-0894
Sag Harbor Synagogue	631-725-8021
St. Andrew Church.....	631-725-0123
Triune Baptist Church	631-725-0486

Shelter Island

Our Lady of the Isle Church	631-749-0001
Shelter Island Presbyterian Church.....	631-749-0805
St. Mary's Episcopal Church	631-749-0770

Southampton

Chabad of Southampton Jewish Center631-287-2249
 First Baptist Church631-283-4651
 First Presbyterian Church631-283-1296
 Greek Orthodox Church of the Hamptons631-283-6169
 Hispanic Apostolate631-283-4379
 Sacred Hearts of Jesus and Mary Church631-283-0097
 St. John’s Episcopal Church631-283-0549
 United Methodist Church of Southampton.....631-283-0951

Southold

First Presbyterian Church of Southold.....631-765-2597
 Shiloh Baptist Church631-765-3388
 St. Patrick’s Church631-765-3442

Watermill

Chabad of Watermill631-726-3046
 Siena Spirituality Center631-726-4740
 The Hamptons Alliance Church.....631-726-4889

Westhampton Beach

Immaculate Conception Church631-288-4188
 St. Mark’s Church631-288-2111
 The Westhampton Synagogue.....631-288-0534
 Westhampton Beach Presbyterian.....631-288-2576

Tip #13 People-to-People Spiritual Support

The churches and houses of worship on the East End are another resource for cancer patients and their caregivers. There are churches for many different faiths, and most congregations are growing and energetic. Their clergy also have a long history of cooperating with one another, through interdenominational groups like Clericus.

Within these houses of worship, the cancer patient will find people of faith, but also people who really care about other people, including total strangers.

In other words, it is a place of empathy and people-to-people relationships which are mutually supportive. Being part of those relationships can be a valuable “life skill” for cancer patients.



CHAPTER 14

COMMUNITY SUPPORT ORGANIZATIONS



Sometimes it will be hard to predict where your journey with cancer will take you and what you will need along the way. Knowing your community resources and the wide range of options available to you may provide you with a sense of empowerment and control.

Challenge: How can I find the organizations on the East End that will address my various needs as I cope with cancer?

Solution: There are a number of community organizations that can provide support for your changing needs. As you face your own unique challenges dealing with cancer, tapping into the network of services that exist on the East End may strengthen your life preserver and connect you with others who face similar challenges.

Community Advocacy

Knowing your rights as a cancer patient and accessing services can be complicated. There are organizations on the East End that focus on empowering, educating and supporting people as they face the challenges of coping with cancer:

American Cancer Society

Cancer Survivors Network, online community (Eng. & Span.) to find hope and inspiration. Provides resources in the local community by maintaining a comprehensive list of organizations that cancer patients and their families can benefit from.

75 Davids Drive

Hauppauge, NY 11788..... 631-436-7070

www.cancer.org 800-ACS-2345

East Hampton Meals on Wheels

Delivers meals to homebound clients in East Hampton. Contact the Dept. of Human Services in East Hampton to schedule delivery. The cost is \$8/day for two meals. No age limit.

33 Newtown Lane, Suite 2

East Hampton, NY 11937 631-329-1669

Chapter Fourteen Community Support Organizations

East Hampton Town Dept. of Human Services

300 Pantigo Place

East Hampton, NY 11937 631-329-6939

Hispanic Apostolate

Spanish-speaking patient advocate

168 Hill Street

Southampton, NY 11968 631-283-4379

Lung Cancer Alliance

National not-for-profit organization dedicated solely to helping people with lung cancer, and those who are at risk for the disease, improve the quality of their lives through advocacy, support and education.

www.lungcanceralliance.org 800-298-2436

North Fork Breast Health Coalition

P.O. Box 525, ste. 6

Riverhead, New York 631-208-8889

www.northforkbreasthealth.org

South Fork Community Health Initiative *(Spanish-speaking personnel)*

Ongoing advocacy voice for the healthcare needs of the community. Provides educational programs, family and individual counseling, as well as outreach and safety programs.

200 Pantigo Place, Suite M

East Hampton, NY 11937 631-329-2425

www.sfchi.org

Southampton Town Dept. of Human Services

116 Hampton Road

Southampton, NY 11968 631-287-5734

Southold Town Dept. of Human Services

Karen McLaughlin, *Director*

750 Pacific Street

Mattituck, NY 11952 631-298-4460

Suffolk County Office for the Aging

The Suffolk County Office for the Aging coordinates a network of services available to seniors. These include assistance, social and recreational programs geared to help you live independently and actively in your community.

Case Management631-852-1420

Family Caregiver Support Services

Helps sustain family caregivers who are caring for an elder relative with chronic illness or disability.631-853-8200

The National Association of Puerto Rican/Hispanic Social Workers

(Spanish-speaking)

Private practice social workers. Services offered are based on individual needs.

Contact them for more information. Most insurance accepted.

www.naprhsw.org631-864-1536

Cancer Support Groups

Another way you may find extra support is by joining a support group. This is a place where people who have similar experiences can come together to express thoughts, feelings, concerns as well as receive helpful information. The shared experience can be a powerful source of hope and strength. Groups may be facilitated by a professional or patient volunteers. Many support groups are now available online via the Internet. For details on specific support groups in your area check the listing below.

A.H.E.A.D. (African-American Health Education and Development)

Breast Cancer Support group516-538-0656

Bay Shore/ Brentwood Breast Cancer Coalition

Latino Cancer Support Group

Carmen Bryant631-273-9252

Brain Tumor Society

Adult Brain Tumor Support Group, first Thursday of every month from 7-9 p.m.

Old Bethpage Library, 999 Old Country Road

Plainview, NY 11803

Billie Wilczek.....516-747-8749

Donna Lankford.....516-922-4134

Camp Adventure

The American Cancer Society offers a free, one week sleep-away program for cancer patients and their siblings on Shelter Island for one week in August (ages 6-18). Volunteers and support always needed.

For more information, please call 1-800-227-2345
www.cancer.org

Camp Good Grief

A bereavement summer camp for children who have lost a parent.

Sarah Zimmerman..... 631-288-8400

CancerCare

Provides counseling by professional oncology social workers to all those affected by cancer. Financial assistance and educational programs are offered as well. Group counseling is also available in person, over the phone, and online to individuals. Extensive telephone education workshops offer a wealth of information by experts in the field and are easily accessible and available.

Theodora Ziongas, Regional Director.

20 Crossways Park North, Suite 110

Woodbury, NY 11797

www.cancercare.org 1-800-813-HOPE(4673)

Colon Cancer Network

Colorectal support group

Contact Patricia Dunn for more information

longisland@colorectal-cancer.net

Ellen's Well

Support and Wellness groups, Yoga and Meditation

Southampton Hospital

Southampton, NY 11968..... 631-726-8606

Fighting Chance - *Hope, Health and Healing; a monthly educational support group for cancer patients and survivors, meets at the Fighting Chance office. Prostate cancer group meets Thursdays, once a month. New groups are formulated according to need.*

For further information call Karrie Robinson, L.C.S.W. -R or William Di Scipio, Ph.D.

134 Bay Street, Suite 201, Sag Harbor NY..... 631-725-4646

www.fightingchance.org

Fortunato Breast Health Center

Breast Cancer Support Group

Port Jefferson, NY 11777 631-476-2771

Good Samaritan Hospital Medical Center

Cancer support groups available for patients, family members and friends. Groups are run by trained professionals in a strictly confidential setting.

631-376-4444

Gynecologic Oncology Support Group

Meets the last Tuesday of the month 7:00 - 9:00 p.m.

994 Jericho Turnpike, Suite 103

Smithtown, NY 11787 631-864-5440

Huntington Hospital

Offers several support groups including breast cancer and prostate cancer groups as well as general oncological and bereavement support groups.

270 Park Ave., Huntington, NY 11743 631-351-2568

Joshua's Place

A self-help support group, led by cancer survivors. Provides an atmosphere of love & community, where people can come together to move towards inner wholeness.

30 Sanford Place

Southampton, NY 11968 631-287-4100

North Fork Breast Health Coalition

Works to encourage and assist in the prevention, early intervention, and cure of breast cancer through advocacy, awareness, networking, and research.

Breast Cancer Support Groups 631-727-1569

Prostate Cancer Support Group - Man to Man

Meets the first Monday of the month - 5:30 - 7:00 p.m.

Stony Brook University Cancer Center 631-444-2552

Sisters of Greater New York, Long Island Chapter

African-American Breast Cancer Survivor Support Group.....

516-385-5495

Chapter Fourteen **Community Support Organizations**

The Leukemia and Lymphoma Society – Long Island Patient Services

The Long Island Chapter works with patients in Nassau and Suffolk counties offering family support, caregiver support and parents of children with cancer telephone support groups. The peer counseling program, First Connection, connects a newly diagnosed patient with a trained volunteer who has experienced a similar situation. Trained volunteer survivors offer support and information to individuals or patients' family members who are learning to cope with leukemia, Hodgkin's and Non-Hodgkin's lymphoma and myeloma. Presents educational programs on blood cancers as well as survivorship issues. Programs open to patients, families and health care professionals. The Society also offers limited financial aid for patients diagnosed with a blood cancer.

Patient Services Manager-Karen DeMairo

555 Broad Hollow Road, Suite 403

Melville, NY 11747.....631-752-8500

The Witness Project of Long Island

Breast cancer awareness program for African American communities

HSC Level 3, Room 92

Stony Brook, NY 11974-8036631-444-7789

Time for Teens

A non profit organization dedicated to providing teenagers with a sensitive, caring, and creative environment for healing. Focus is on the needs of teens related to bereavement and loss through education and counseling.

Laraine Gordon, L.C.S.W.

Southampton, NY 11968.....631-338-7258

www.time4teens.org

Upper GI Cancer Support Group

Meets the second Wednesday of the month - 7:00 p.m.

Stony Brook University Cancer Center631-444-4000



HOME HEALTH SERVICES & SPECIAL EQUIPMENT

Functioning at home can be a challenge while living with cancer. You may find that you or your loved ones may need assistance with self-care, everyday household chores, in-home medical care and may require special medical equipment.

Challenge: How do I find the appropriate home healthcare support?

Solution: Your home healthcare needs will change as your cancer treatment evolves and changes. At certain stages you may find that establishing a network of family and friends to provide minimal assistance in the home is sufficient. As your treatment progresses, you may find that more care is required.

Aides at Home

Committed to the delivery of the finest homecare services possible.

Endeavors to train and hire quality personnel to care for clients.

31 West Main Street, Suite 201

Patchogue, NY 11772 631-447-1480

www.aidesathome.com

All-Care Medical Products Corps

Certified Prosthetic; Orthotist & Fitters on staff. Free pick-up and delivery

79 Deer Park Avenue

Babylon, NY 11702..... 631-587-4170

At Home Services

Committed to providing affordable non-medical assistance to those in need. Full or
part time. 631-477-3095

Chapter Fifteen: **Home Health Services & Special Equipment**

Brookhaven Memorial Hospital Home Health Agency

Services may help to shorten or prevent an inpatient stay in the hospital, provide a smooth transition from the hospital to the home, prevent or delay placement in a nursing facility and reduce the stress on the patient and family.

103 West Main Street
Patchogue, NY 11772631-758-3600
www.brookhavenhospital.org/services/homehealth.html

Comfort Keepers

Comforting solutions for in-home care, includes in-home companionship and care services; 24 hr or live-in care (available in most areas).

31 Main Road, Suite 9
Riverhead, NY 11901631-369-6080
www.comfortkeepers.com

Companion HomeCare631-884-0005
West Babylon, New York 11707

Dominican Sisters Family Health

Community-based, certified, non-profit Home Health Agency. Offers compassionate, professional, wholistic and family-focused home healthcare to persons in need. Services foster a quality of life, which promotes human growth and independence.

103 West Montauk Hwy., Hampton Bays, NY 11946631-728-0181
360 Main Street, Wainscott, NY 11976631-267-2004
www.dsfs.org

East End Nursing Service631-725-2713
Referral service for private nurses.

Family First Home Companions

Provides compassionate, supportive service, including transportation to doctors' appointments. Competitive rates, on-call service 24/7.

Call Jennifer Bonora631-224-7433
300 Motor Parkway, Suite 200
Hauppauge, NY 11788

Gentiva

877 East Main Street, Riverhead, NY 11901631-727-5353

Hampton Home Care

Durable Medical Equipment

16 Hampton Road
Southampton, NY 11968631-283-8211

Extended Care Health Services

67 Middle Country Road, Middle Island, NY 11953..... 631-698-3838

Lehneis Orthotics & Prosthetics

524 E. Main St.
Riverhead, NY 11901..... 631-369-3115
www.lehneis.com

Lewin Services and Medical Supplies

(Adjacent to Wal-Mart on Route 58)
165 Oliver Street
Riverhead, NY 11901..... 631-727-7006/76
www.lewinmedical.com

Peconic Bay Homehealth Services

Meeting the homecare needs of patients and the community through direct care, innovation, education and commitment. The goal of Peconic Bay Homehealth Services is to maximize the health, comfort, mobility and independence of each patient through direct skilled care and education. Home Health Aides, Trained Nurses and Social Workers available.

Peconic Bay Medical Center

1300 Roanoke Ave., 3rd Floor,
Riverhead, NY 11901 631-548-6432
www.peconicbaymedicalcenter.org/csh-peconic_homehealth.htm

Personal Touch

Provides care that encourages the safe and cost-effective delivery of homecare services, maximizing patient autonomy and coordination of community and agency resources, to decrease burden and unnecessary duplication of services, thereby promoting positive patient outcomes.

640 Montauk Hwy.
Shirley, NY 11967..... 631-281-0157
www.pthomecare.com

Recco Home Care

472 Montauk Hwy., Unit 5
East Quogue, NY 11942..... 631-653-5500

Shene Nursing Service

Provides professional nursing, social work, live-ins full/part time, and ongoing medical treatments. For assessment and further information please call:

419 Montauk Highway
Wainscott, NY 11975 631-537-0000
www.shenenursingservice.com

T.L.C. Home Health Care Providers

Provides personal care, critical care, long & short term care, and light house keeping.

Please contact Mary631-827-8471

References Available

Utopia Home Care Inc.

Committed to providing patients and their families with quality services that demonstrate compassion, professionalism and a dedication to the highest standards.

116 E. Main Street

Patchogue, NY 11772631-654-8006

180 Old Country Rd

Riverhead, NY 11901.....631-369-5500

www.utopiahomecare.com

Westhampton Care Center

78 Old Country Road

Westhampton, New York 11977.....631-288-0101

Tip #14 The Costs of “Custodial” Care

Most healthcare insurance only covers “skilled” care for cancer patients. That means doctors, in-home nursing visits, skilled nursing homes and the like.

But, what is called “custodial” care – such as helping the cancer patient with housekeeping, bathing and getting to the bathroom – is typically not covered by insurance.

Custodial care from paid caregivers can quickly become very expensive – especially if the cancer patient is elderly, exhausted by his or her therapy and needs someone at bedside 24 hours a day. One way to reduce costs is for family and friends to assume daytime caregiving duties, although that requires advance planning and lots of good communication.

In addition to financial demands, custodial care also can create emotional stress for the patient’s family. It is important for family members to have support and outlets as they continue caregiving.



ASSISTED LIVING/NURSING HOMES

Sometimes the care that we need will exceed the resources and capabilities of our homes, families and friends. In these instances, locating round-the-clock care in assisted living or nursing home facilities may be an important option to consider.

Challenge: How do I find a nursing home/assisted living center that I feel comfortable with for my loved one or for me?

Solution: Making the decision to move to a nursing home or assisted living facility is a very difficult one. Ensuring that you select a facility that will provide the highest standard of care for you or your loved one may provide some comfort. All nursing homes require a license from the Department of Health of the State of New York. If you have questions about a particular nursing home, call the Department of Health at 1-800-425-0316. You can also visit www.medicare.gov/nhcompare/home.asp, which is a government sponsored website with helpful tips on evaluating nursing homes.

Brookhaven Health Care Facility

Committed to value and respect towards each individual resident, patient, employee and family member.

801 Gazzola Drive

East Patchogue, NY 11772.....631-447-8800

www.mcguiregroup.com

Peconic Landing

Dedicated to helping residents realize their full potential throughout retirement while maintaining their privacy, independence, security and peace of mind. PL is committed to providing superior healthcare for life, financial protection from high healthcare costs, and equity benefits that come with cooperative ownership.

1500 Brecknock Road.....888-273-2664

Greenport, NY 11944.....631-477-4217

www.peconiclanding.org

San Simeon By the Sound

61700 Route 48

Greenport, NY 11944 631-477-2110

Southampton Care Center

Provides short-term rehabilitative and long-term care for adults. Center residents receive nursing care, specialized rehabilitation services, recreational therapy, dietary services and social services tailored to meet their needs.

330 Meeting House Lane

Southampton, NY 11968..... 631-283-2134

Westhampton Care Center

78 Old Country Road

Westhampton, NY 11978 631-288-0101

Tip #15 Calvary Hospital (a very special place)

No matter how hard cancer patients fight, we know that sometimes the disease wins out. The last weeks can be difficult for cancer patients who would prefer a hospital setting – but cannot get a bed because the patient’s “vital signs” are too positive.

Where do these cancer patients go for comfort? One answer is Calvary Hospital. Its main facility is located in the Coop City areas of the Bronx and serves residents of the Tri-State area. Terminal cancer patients on the East End of Long Island should consider Calvary to be an accessible resource.

Calvary describes itself as “the nation’s only acute care specialty hospital devoted exclusively to the palliative care of adult patients in the advanced stages of cancer.”

Like hospice, Calvary provides state-of-the-art pain relief; but Calvary does so in a medical facility setting.

For more information call Calvary at 1-718-863-6900 or visit their website (www.calvaryhospital.org).



At some point during our journey with cancer we may face the very difficult decision of transitioning from curative cancer treatments to palliative care, which is care given to improve one’s quality of life. During this phase we may decide that a hospice care provider can support this choice most effectively.

Challenge: How do I find a hospice care provider that will meet my needs?

Solution: The choice to use hospice can be a deeply painful and difficult one. Selecting a provider that will be able to support your physical, emotional, psychological and spiritual needs is crucial.

Brookhaven Memorial Hospital Medical Center Hospice Office

Hospice is a compassionate program for those with a limited life expectancy in a homecare setting or a contracted skilled nursing facility. Hospice services are coordinated by an interdisciplinary team (physician, nurse, home health aide, nutrition counselor, social worker, pastoral care counselor and trained volunteers) who ensure continuity of patient and family care. Supportive Care, a newly developed program, offers services to terminally ill patients and their families who are not yet able to accept the concept of hospice care. Medicare, Blue Cross, Medicaid and other health insurance companies cover hospice services. Care will be provided regardless of a person’s ability to pay.

105 West Main Street
Patchogue, NY 11772 631-687-2960
www.brookhavenhospital.org/services/hospice.html

East End Hospice

Home healthcare, with short-term hospital stay when needed, for the people of the Hamptons and surrounding Long Island towns. Medicare, Medicaid, Blue Cross and most private insurance carriers have provision for payment for hospice care. No one will be denied care by East End Hospice because of inability to pay.

481 Westhampton Riverhead Road
Westhampton Beach, NY 11978 631-288-8400

Tip #16 East End Hospice, Affordable for All

For cancer patients who are terminal, care within a hospice program is well worth considering. East End Hospice (located in Westhampton) stands out as an extraordinary resource by any standard.

East End Hospice serves about 400 patients a year of which about 65% are suffering from cancer. It aims to meet all of a patient's end-of-life needs with a team of doctors (including pain management specialists), hospice nurses, homecare aides and volunteers.



INTERNET RESOURCES



The Internet can be a powerful tool for gathering medical information, locating resources, learning about treatment options and finding support groups. In fact, many cancer patients and caregivers feel empowered as they use the Internet to educate themselves on the wide range of cancer-related issues they face.

However, wading through the sheer volume of information available on the Internet can be overwhelming. Having the tools to assess the credibility, accuracy and authenticity of a website will help you gather accurate and reliable cancer information. Here are some Internet tips to keep in mind:

How to evaluate a website:

ACCURACY

Is the web information correct? Verify that the links on the website are active and up to date. Look for date “last updated” usually at the bottom of the web page to see how current the information is.

CREDIBILITY

What kind of website are you visiting? By looking at the domain name you can determine the type of site you are on and the kind of information that might be presented. Some common domain names include:

- **.edu** – *educational sites - Educational domains usually support knowledge and learning.*
- **.gov** – *government sites – Commonly include public information, as well as statistical data.*
- **.org** – *nonprofit organization sites - Organizational sites may present information supporting a particular cause or representing a particular point of view.*
- **.com/.net** – *commercial and network sites. Commercial and network domains often promote business and/or products.*

Determine the bias of information presented. Are advertisements distinctly separate from content? Do any of the sponsors sell products related to site content? Are there any conflicts of interest among the sponsor of the site, advertisers on the site and the information on the site?

AUTHENTICITY

Verify the legitimacy of a person or organization by contacting the organization through its mailing address or phone number. Email can be created by anyone and therefore is not a sufficient means of verifying an organization's identity. Contact information can usually be found on the homepage or "About Us" or "Contact" pages of the site.

Remember: If you do not have a computer but would like to surf the Internet, you can visit your local public library. They provide free access to the Internet and the librarians may be available to assist in you in your research.

Below you will find a list of trusted, credible websites on a range of important cancer-related topics. Remember that the Internet is not a substitute for receiving appropriate medical care.

General Cancer:

Support, Information, Education & Financial Assistance

American Cancer Society - Publications, Patient Navigation, Road To Recovery/Transportation Program, Clinical Trials Matching & Referral Service, Financial Assistance, Survivors Network (Eng., Span.), Reach To Recovery, Look Good, Feel Better, Camp Adventure, Wigs (for those with limited insurance or financial resources).

www.cancer.org

Association of Cancer Online Resources - Information, access to over 100 cancer-related mailing lists, support, resources.

www.acor.org

Association of Oncology Social Work (AOSW) - a non-profit organization dedicated to the enhancement of psychosocial services for people with cancer and their family members. The AOSW website links to oncology resources such as cancer organizations and disease-specific sites for adults and children.

www.aosw.org

CancerCare - Information, support services, publications, educational workshops, resource database, financial assistance, links to other cancer-related web sites.

www.cancercares.org

Cancer Hope Network - Support Services

www.cancerhopenetwork.org

Cancer.com - Maintained by Orthobiotech Products: extensive listing of links to cancer-related sites for information, advocacy, education, resources, and support.

www.cancer.com

Cancereducation.com - General info website, includes transcripts and webcasts of many useful programs.

www.cancereducation.com

Cancer Information Service - Maintained by the Cancer Information Service: Information, education, links to other cancer-related sites.

www.cancerinfonet.org

Cancer.net, Patient information website of the American Society of Clinical Oncology. Formerly People Living with Cancer website.

www.cancer.net

Cancer Research and Prevention Organization - Information, education, links, support.

www.preventcancer.org

Cancersymptoms.org - Information, Q&A about several common cancer and treatment-related symptoms.

www.cancersymptoms.org

Clinicaltrials.gov - A service of the National Institutes of Health Information about clinical trials, database of clinical trials.

www.clinicaltrials.gov

Cycle of Hope - Information, resources, support, links.

www.cycleofhope.com

Fighting Chance - Counseling and Resource Center for cancer patients

www.fightingchance.org

Chapter Eighteen: Internet Resources

Gilda’s Club - Information, resources, links, support.

www.gildasclub.org 888-GILDA-4-U

Look Good Feel Better - Cosmetology and haircare during cancer treatment, provided by the American Cancer Society. Program is offered on both the North and South Fork of Long Island. A free gift tote bag of \$250 in cosmetics is provided to each participant.

www.lookgoodfeelbetter.org 800-395-LOOK

Medem.com - Information, education, library resources.

www.medem.com 877-926-3336

Medlineplus - Information, links, resources.

www.nlm.nih.gov/medlineplus

MD Anderson Cancer Center - Information, education, support and resources.

www.mdanderson.org

National Cancer Institute - Information (cancer by type, research, clinical trials), education, publications.

www.cancer.gov..... 800-4-CANCER

Oncolink - Information, education, support and resources.

www.oncolink.upenn.edu

The Oncology Nursing Society - a professional organization of more than 33,000 registered nurses and other healthcare providers dedicated to excellence in patient care, education, research, and administration in oncology nursing.

www.ons.org

National Coalition of Cancer Survivorship (NCCS) - Information, advocacy, resources, links, support.

www.canceradvocacy.org 301-650-9127



CANCER SPECIFIC INFORMATION AND SUPPORT

Bladder Cancer

Bladder Cancer Web Café

www.blcwebcafe.org

Information, resources, email discussion list, support.

United Ostomy Association

www.uoa.org 800-826-0826

Information, support, education, advocacy.

Brain Tumor

National Brain Tumor Foundation

www.braintumor.org 800-934-2873

Research, information, resources.

American Brain Tumor Association

www.abta.org

Research, information, resources.

The Traumatic Brain Injury Helpdesk for Caregivers

www.tbihelp.org

Information on traumatic brain injury, support, education, resources.

Clinical Trials and Noteworthy Treatments for Brain Tumors

www.virtualtrials.org

Information, resources, support, links.

Breast Cancer

SHARE

www.sharecancersupport.org 866-891-2392

Self-help for women with breast and ovarian cancer.

Susan G. Komen for the Cure

www.komen.org 800-462-9273

Aims to eradicate breast cancer as a life-threatening disease by advancing research, education, screening and treatment.

Chapter Eighteen: Internet Resources

Y-ME National Breast Cancer Organization

<http://www.y-me.org/>

Support, information and resources.

Cervical Cancer

The National Breast and Cervical Cancer early detection program

www.cdc.gov/cancer/nbccedp/888-842-6355

Provides screening services to underserved women.

The National Cervical Cancer Coalition

www.ncc-online.org/

Advocacy and medical information on cervical cancer.

Colorectal Cancer

Colon Cancer Alliance

<http://www.ccalliance.org/>

Information, support and resources

Colorectal Cancer Network

<http://www.colorectal-cancer.net/>

Information, support and resources

Complementary Therapies

Memorial Sloan-Kettering Cancer Center, Integrative Medicine Service

www.mskcc.org/aboutherbs

Information about herbs, botanicals and other products

Gynecological

Ovarian Cancer National Alliance

www.ovariancancer.org202-331-1332

Information, education, support, links

SHARE

www.sharecancersupport.org866-891-2392

Self-help for women with breast and ovarian cancer.

The Women's Cancer Network

www.wcn.org

Information, education, support, links.

Kidney Cancer

The Kidney Cancer Associatoin
www.kidneycancer.org 800-850-9132
 Information on medical interventions, research and advocacy on behalf of patients

Leukemia, Lymphoma, Myeloma

Leukemia and Lymphoma Society
www.leukemia-lymphoma.org 800-955-4572
 Information, education, resources, financial assistance, support

The Bone Marrow Foundation
www.bonemarrow.org 800-365-1336
 Information, education, support, resources, financial assistance

National Marrow Donor Program/Be The Match Registry
www.bethematch.org 800-627-7692
 Connect patients, doctors, donors and researchers to resources they need to help more people live longer, healthier lives.

Lymphoma Research Foundation
www.lymphoma.org 800-235-6848
 Information, education, support, resources, advocacy

Multiple Myeloma Program, The Cleveland Clinic Foundation
www.ccf.org/cc/mm 800-223-2273
 General information on clinical trials, research and medical developments

International Myeloma Foundation
www.myeloma.org 800-452-2873
 Free informational packet, hotline numbers, support group listings, info about patient to patient directory

Liver Cancer

LiverTumor.org
www.livertumor.org/default.asp
 Information about primary and metastatic liver tumors. Lists and explains treatment options.

Chapter Eighteen: Internet Resources

Lung Cancer

Lung Cancer Alliance

<http://www.lungcanceralliance.org/>

Information, education, support and resources.

Lung Cancer Information Library: Medicine OnLine

www.meds.com/lung/lunginfo.html 203-375-7300

Comprehensive information and frequently asked questions on all types of lung cancer, screening and treatment.

Lung Cancer Research Foundation

www.lungcancerresearchfoundation.org 212-332-4403

Grass roots organization in support of new and innovative research.

Pancreatic Cancer

Lustgarten Foundation

www.lustgarten.org 516-803-2306

New information for people with pancreatic cancer.

The Johns Hopkins University Pancreatic Cancer Home Page

www.path.jhu.edu/pancreas

Information on treatment, research and links to other pancreatic cancer websites.

Prostate

Us Too

www.ustoonewyork.org 212-946-1494

Prostate cancer survivor support and educational group.

Prostate Cancer Foundation

www.capcure.org

The association for the cure of cancer of the prostate. 800-757-2873

Oral, Head and Neck Cancer

SPOHNC (Support for People with Oral, Head and Neck Cancer)

www.spohnc.org 800-377-0928

Newsletter, resource guide, cookbook.

The Oral Cancer Foundation

www.oralcancer.org

Information, support, resources, email newsletter.

Sarcoma

Kristen Ann Carr Fund Sarcoma Forum
www.sarcoma.com

Skin Cancer

The Skin Cancer Foundation
www.skincancer.org 800-SKIN-490
Up-to-date information on the prevention, diagnosis and treatment
of skin cancer.

Melanoma Patient’s Information Page
www.mpip.org
Provides support and information to melanoma patients.

Thyroid

Thyroid Cancer Survivors Association
www.thyca.org 877-588-7904
Supports education, research and communication among patients,
physicians and families.

Testicular

Testicular cancer Information from the National Cancer Institute
<http://www.cancer.gov/cancertopics/types/testicular>

Further Internet Resources

Young Adults Living with Cancer

The Kristen Ann Carr Foundation
www.sarcoma.com

The Lance Armstrong Foundation
www.livestrong.org

The Leukemia and Lymphoma Society
www.lls.org

Chapter Eighteen: Internet Resources

Planet Cancer

www.planetcancer.org

Support, information, message boards.

The Sam Fund

www.thesamfund.org

Support scholarships, links for young adults with a history of cancer.

The Ulman Fund

www.theulmanfund.org

Support, information, message boards, scholarship fund.

Rolling to Recovery

www.rollingtorecovery.org

Colon cancer specific links to information.

Young Survival Coalition

www.youngsurvival.org

Breast cancer specific (for women under 40) support, information, message boards, advocacy.

Lymphedema Management

National Lymphedema Network

www.lymphnet.org 800-541-3259

Information, resources, research, support.

New York University/ Rusk Institute

www.rusknyu.org

Licensed Therapists.

New York City Lymphedema Support Group

www.nyclymph.freesevers.com 212-717-4810

Lymphatic Research Foundation

www.lymphaticresearch.org 516-625-9675

Research site seeking people with lymphedema to register on their site.

Circle of Hope, Lymphedema Foundation, Inc.

www.lymphedemacircleofhope.org 203-758-6138

Resources, education.

Caregiver Information

National Family Caregiver Association

www.nfcacares.org 1-800-896-3650

Information, advocacy, message boards, publications.

National Alliance for Caregiving

www.caregiving.org

Information, suggested reading, resources.

Family Caregiver Alliance

www.caregiver.org 415-434-3388

Shared Experience

www.sharedexperience.org

Resources, support.

Well Spouse

www.wellspouse.org

Support, information, internet chats, message boards.

Soaring Words

www.soaringwords.org

Support for parents and children when a child is ill.

Hospice and Palliative Care

National Hospice and Palliative Care Organization

www.nhpco.org 703-837-1500

Information, program locator.

National Hospice Foundation

www.hospiceinfo.org 703-516-4928

Information, resources, benefits, program locator.

Hospice Web

www.hospiceweb.com

Information, hospice locator.

Hospice Net

www.hospicenet.org

Information, support.

Chapter Eighteen: Internet Resources

Beth Israel Hospital, New York City

www.stoppain.org

Information, support, education, resources, online conferences.

Growth House

www.growthhouse.org

Information, education, chat rooms.

American College of Physicians

www.acponline.org/public/h_care

Home Care Guide for Advanced Cancer: A guide for family, friends, and loved ones caring for a person with advanced cancer at home.

Pain Management Issues

Partners Against Pain

www.partnersagainstpain.com

Information, education, links to pain management resources and support groups.

Pain.com

www.pain.com

Information, education, message boards, links.

Insurance/Disability/Financial

Social Security

www.ssa.gov 800-772-1213

Medicare Web Site

www.medicare.gov 800-MEDICARE

Information on Medicare insurance policies.

Medicare Rights

www.medicarerights.org

Largest independent source of Medicare information and assistance in the U.S.

Gay Men's Health Crisis

www.gmhc.org/living/insure.html

Information on disability, insurance and Social Security.

National Institute on Disability and Rehab Research

www.ed.gov/offices/osers/nidrr

Resources, rehabilitation information and advocacy.

New York State Elderly Pharmaceutical Insurance Coverage (EPIC)

www.health.state.ny.us/nysdoh/epic/faq.html

State-sponsored prescription plan for seniors who need help paying for drugs.

Together Rx

www.together-rx.com

Prescription program for senior citizens.

Benefits Check Up

www.benefitscheckup.com

Website providing public benefits screening.

Families USA

www.familiesusa.org

Information and resources on healthcare programs and legislation on a state-by-state basis.

Family Health Plus

www.health.state.ny.us/nysdoh/fhplus/

Affordable family health insurance; free quotes.

Employment/Legal Rights

Law Help

www.lawhelp.org/NY

Legal assistance for low-income New Yorkers.

Patient Advocate Foundation

www.patientadvocacy.org 800-846-7444

Information, education and advocacy for cancer patients and all health issues.

Cancer and Careers

www.cancerandcareers.org

Resources and information for working women with cancer.

Post-Treatment Resource Program – Memorial Sloan-Kettering Cancer Center

<http://www.mskcc.org/mskcc/html/19409.cfm> 212-717-3527

Support groups, seminars, workshops, and practical employment and insurance information.

General Services for Children with Cancer and Their Families

Candlelighters Childhood Cancer Foundation
www.candlelighters.org 800-366-2223
Peer support network for parents, newsletter and insurance concerns.

The Children’s Cause, Inc.
www.childrenscause.org 301-562-2765
Dedicated to accessing safer and improved treatment for childhood cancer.

Children’s Organ Transplant Association, Inc. (COTA)
www.cota.org 800-366-2682
Provides fundraising assistance for children and young adults needing life-saving transplants.

Make-A-Wish Foundation of America
www.wish.org 800-722-9474
Grants wishes of children, ages 2-18, with life-threatening illnesses.

Starlight Children’s Foundation
www.starlight.org 800-315-2580
Provides programs addressing social, emotional and medical aspects for children coping with serious illness.

Pediatric Brain Tumor Foundation (PBTf)
www.pbtfus.org 800-253-6530
Provides free educational resources for families; educational scholarship program for pediatric brain tumor survivors.

National Children’s Cancer Society
www.nationalchildrenscancersociety.org
Promotes children’s health, through financial and in-kind assistance, advocacy, education and support.

Tip # 17 Cancer Survivorship & Follow-Up Care

Due to early detection, improved screening and targeted and specialized treatments for cancer, many people are cured of their disease or live with their disease controlled or in active remission.

Once your active cancer treatment is complete, a wide range of information is available to you. To help with this transition go to www.cancer.net. Information such as managing side effects and late effects is available.

It is most important that you develop an individualized aftercare program with your oncologist when treatment ends. Primary care physicians do not necessarily have experience regarding your type of cancer and its side effects. Guidelines for follow-up care include annual tests or procedures.

For further guidance, contact Fighting Chance at 631-725-4646.





TEN FIGHTING CHANCE TIPS FOR COPING WITH CANCER

- Always ask LOTS of questions! Ask questions of yourself, of your family, of your doctor!
- Identify your emotional, physical and spiritual priorities.
- Create a community of friends, family and caregivers to help you meet those priorities.
- Identify what it would mean for you to feel more empowered.
- Find a medical team you feel good about.
- When selecting doctors, find out how much experience he/she has with your particular diagnosis and treatment.
- How comfortable is the doctor with patients obtaining second opinions?
- How well does the doctor answer your questions?
- How willing is the doctor to work as a team with other doctors who are treating you?
- Is the doctor's approach and philosophy consistent with your values?
- Most importantly: trust your intuition. Do you feel comfortable and at ease? Do you feel that the doctor is competent, knowledgeable and caring?

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