

FIGHTING CHANCE

2017

Practical Tips & Strategies
for Cancer Patients
on the East End
of Long Island

*www.fightingchance.org
Hotline: 631.725.4646*

WELCOME . . .

A decade ago my mother, who lived in Sag Harbor, was diagnosed with lung cancer. She lived another 100 days.

We desperately needed someone to patiently educate us about cancer so we could make well-informed decisions about treatment options.

We needed an expert to help navigate the healthcare system, which was overwhelming us with “red tape.”

And we needed a place with professional counselors to help us overcome the feelings of fear and helplessness.

Back then, there was no place to go. Now there is: Fighting Chance.



Duncan Darrow
Founder and Chairman

“For cancer patients the Sag Harbor office of Fighting Chance is like a sanctuary infused with compassion and empathy . . . that alone means a great deal to those who are suffering and I say that based on my service for over 50 years as a Catholic Nun.”



Sister Ann Marino, R.S.H.M.
*Director of the Cormaria Retreat House
& Director Emeritus of Fighting Chance*

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Introduction - Fighting Chance an East End Charity



Fighting Chance is a free-of-charge Cancer Counseling Center operated on a **regional** basis -- focusing exclusively on the five towns which make up the Eastern End of Long Island.

The charity is 501c3-qualified and began serving the East End community in 2002. Since then it has provided professional counseling and other supportive care to over 2,500 newly-diagnosed cancer patients.

Operating on a regional basis means that Fighting Chance has a walk-in storefront-style office (in Sag Harbor) and “boots on the ground” -- meaning healthcare professionals who are in the office everyday available to meet in person with cancer patients and their families. These services, of course, are free-of-charge.

Almost all cancer counseling today (except in some of the largest urban cancer centers) takes place over the telephone or via the Internet -- which includes emails, chatroom and texting. Meeting with your advisor face to face, however, remains the “gold standard” for cancer counseling.

The Fighting Chance community service model also is distinctive because of the extraordinary depth of experience possessed by our healthcare professionals.

Karrie Robinson and Bill DiScipio, for example, together have over 75 years of experience helping patients navigate the cancer journey, and they have worked together at Fighting Chance for almost a decade.

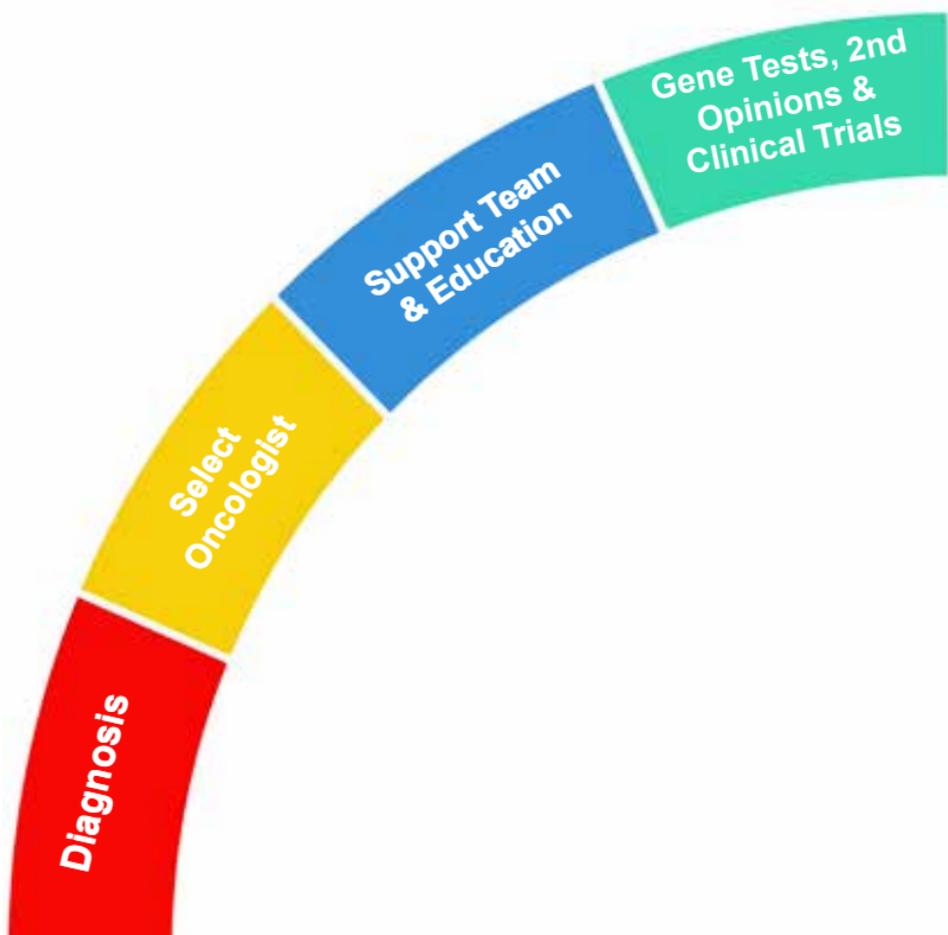
Fighting Chance is governed by a 13-member Board of Directors, we operate on an annual budget of roughly \$500,000 (raised entirely by donations, large and small, and we have an Endowment Fund of \$1,000,000).

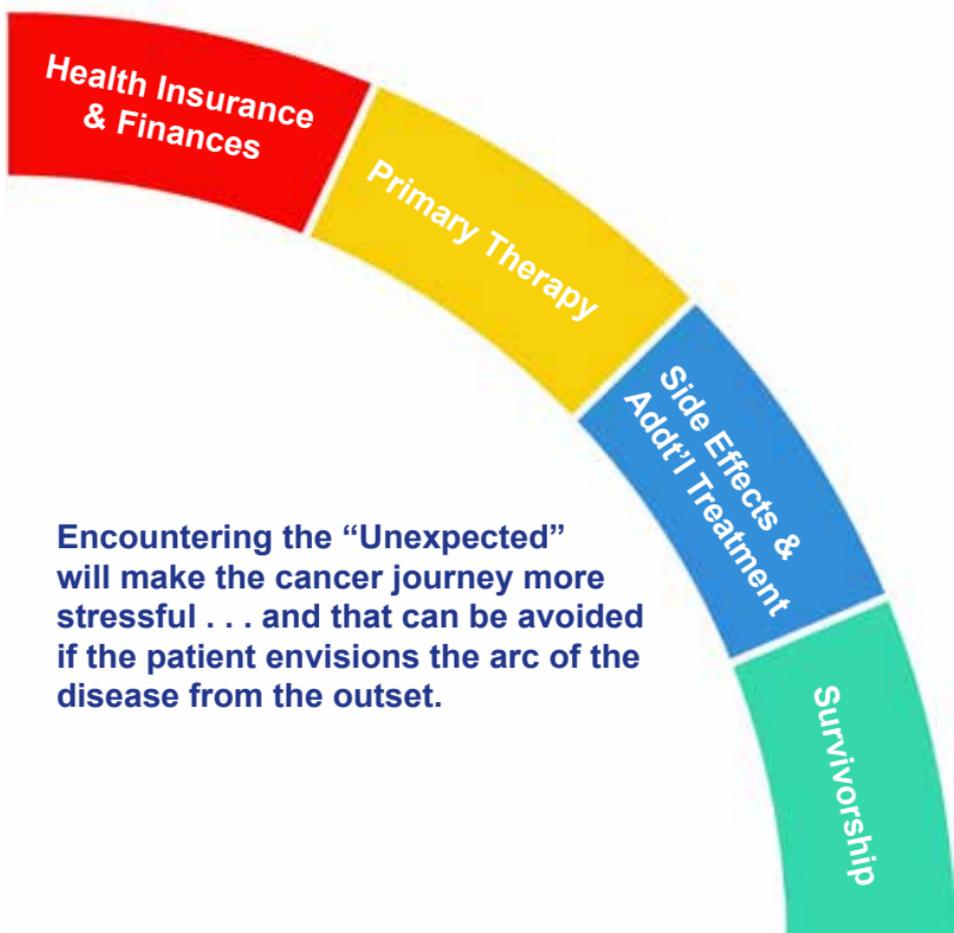


Chapter 1

The “Arc” of the Disease

... thinking of the Cancer Journey in terms of its major segments can make the journey less daunting and more







Group Counseling Room at our Sag Harbor office



Imagine sitting in your doctor's office in one of the many beautiful villages on Long Island's East End. The doctor looks at you across his desk and delivers a message.

"You have cancer." Your world, instantly, is turned upside down. If you are like most patients, 1,000 questions race across your mind, and you are overwhelmed by a fear of the unknown.

Now what? For many patients on the East End, the very first step is to call Fighting Chance. Make an appointment -- the very next day if possible -- with one of our professional and licensed counselors.

You will see either a licensed clinical psychologist with a Ph. D (such as Dr. Bill DiScipio) or an oncology social worker with 20 years of experience (such as Karrie Robinson, LCSW).

The time you spend with these counselors and all the other services at Fighting Chance are **free-of-charge**. And they have been since the day we started in 2002.

If you are diagnosed with cancer you can, of course, help yourself in many ways. Two priorities:

- Use the Fighting Chance counseling process to help you regain your composure, as well as the ability to digest complex information and make what you feel are well informed treatment decisions.
- Understand at the beginning of your journey what the "Arc" of the disease looks like. This will prepare you for challenges that lie ahead and reduce "unexpected" events that can throw you off balance. Again the Counselors at Fighting Chance can be helpful.

- Be on the lookout for tools -- be they counseling advice or educational material -- that can improve the patient's sense of "empowerment." A patient's cancer journey is almost always more successful when they feel that they are helping themselves, albeit with new resources. A good example is this guide -- commonly known as the "Blue Guide," and its companion pamphlet, the "Orange Guide," which provides a host of practical tips for coping with cancer.

A cancer diagnosis, like many other crises that individuals face in life, becomes more manageable once a plan of action has been formulated. In other words, a strategy.

At Fighting Chance we help patients develop a strategy by thinking of their battle with cancer as a "Journey." Then we help them see that the journey can be divided into logical segments. What was depicted at the beginning of this guide were the eight major segments in a successful cancer journey.

Understanding these segments -- and the way that they sequentially follow one another -- helps the patient stay "in the present" and not waste energy and anxiety over segments of the journey that may not even be encountered for many months.

Mapping all of the segments of the journey should help the patient prepare for challenging events that lie ahead and not be caught off balance by "the unexpected."



Selecting an Oncologist

One of the first steps forward in the cancer journey is for the patient to select a lead oncologist. An oncologist is the physician who specializes in treating cancer. There are three types of oncologists:

- Clinical Oncologists.** They treat patients within a clinical or office setting, for the most part, and the treatments primarily entail selection and administration of anti-cancer drugs, such as chemotherapy. They also tend to get quite involved in the diagnosis of the specific cancer attacking the patient and how advanced it has become. It is the clinical oncologist who most often provides the “leadership” for the patient’s medical team

- Radiation Oncologists.** They treat patients through the administration of radiotherapy, which involves a type of high intensity ray that irrevocably damages the DNA that is the central feature of the nucleus of a cancer cell and is essential to that cell’s replication.

- Surgical Oncologists.** When cancer takes the form of a solid state tumor -- for example, a tumor in the colon or lung -- it sometimes can be removed through surgery and the physician performing that procedure is known as a surgical oncologist.

A newly diagnosed cancer patient usually begins seeing a clinical oncologist. The term “clinical” in this setting means that the patient can see the physician in the doctor’s office and the doctor is trained to provide treatment in that setting.

The clinical oncologist usually becomes the “quarter-back” for the patient’s team of doctors, caregivers and other specialists. For example, the clinical oncologist may believe that the first treatment for the patient should be surgery, in which case a surgical oncologist will be introduced as, in effect, a new team member.

Chapter 3 (continued)

Understanding the clinical oncologist's role as a quarterback also has important implications for cancer patients on the East End.

There are a few clinical oncologists -- less than 10 - whose main offices are located on the East End.

Consequently, if the newly-diagnosed cancer patient wants their clinical oncologist to serve as quarterback and have an office in a nearby East End location, they will find the choices to be limited. Those choices are listed in Chapter 5 of the companion Blue Guide.

On the other hand, if the patient faces a rare form of cancer they may be forced to look to the Stony Brook Cancer Center, or a large facility in New York City, in order to find a specialist who can orchestrate their battle with the disease.

If the principal physician is in New York City the cost of transportation via Hampton Jitney is not insignificant. But free bus tickets for patients often can be picked up at the offices of Fighting Chance.

Assembling a Support Team and Education



The Patient's Team

1. Your Family Doctor. Usually his or her specialty is internal medicine and often he or she is the one who first learned of your disease and said, “You have cancer.” In many cases the family doctor has treated the patient for years and hence has invaluable insight into their medical history which may bare on the therapeutic pathway best suited for treating the patient’s cancer.

2. Oncology Specialists. A clinical oncologist is usually the team leader and can dispense chemotherapy. If the tumor can be removed through surgery, then the team will include a surgical oncologist. A radiation oncologist will be part of the team if radiotherapy is also necessary.

3. Oncology Social Worker and Patient Navigator. The social worker meets with the patient frequently during a multi-week course of medical treatment and helps manage issues like anxiety and stress. The navigator also helps the patient negotiate around barriers to quality health care such as bureaucratic red tape, transportation and other logistics.

4. Friends & Family. Cancer is often said to be a “family disease” so if a patient has, for example, a spouse and children, they are going to be impacted no matter what. Family and friends also are a vital source of moral support and encouragement.

A cancer patient's "Team" is his or her multi-purpose support system and a team that is effectively assembled will give the patient an extra edge in battling the disease.

The first member of the team typically is the patient's main caregiver -- in most cases a spouse, grown child or other family member. He or she will accompany the patient to many doctor appointments, help coordinate transportation, and handle countless other chores of daily living where the patient now requires assistance.

The next step usually is to confirm that the patient's primary care physician has insights that are still valuable and hence that doctor should be integrated as another member of the patient's team. Indeed, in many cases someone gets the news, "You have cancer" from their primary care physician.

Often the primary care physician suggests a clinical oncologist for the patient and an interview follows. It is extremely important to have a strong rapport between the patient and the lead oncologist. At this stage of the cancer journey you often see the patient interview several different oncologists before deciding who will join the team.

Once the patient selects a lead oncologist the patient may obtain a second opinion and decide that the doctor who provided it would be better suited to the patient's needs -- in which case there is a change in team composition.

Finally, the patient should have someone who can counsel them about the psychological stress of a cancer diagnosis and be available for a frequent, if not daily, dialogue. That is where Fighting Chance comes in with its oncology social workers and clinical psychologists who, as a team, have over 100 years of experience in helping patients navigate the cancer journey. Their services, because Fighting Chance is a charity, are always free-of-charge.

“cancersimplified” . . . a Web-Based Learning System

Most of the patients who come to Fighting Chance shortly after their cancer diagnosis know very little about the disease. Some of those patients want to learn more about the disease and that thirst for knowledge often is shared by their family members -- especially teenagers who are part of the “tech savvy” generation and want a web-based learning system.

In response to this interest, Fighting Chance decided, in 2008, that we would design our own unique web-based learning system. We called it “cancersimplified.” It has its own website (www.cancersimplified.org) and the website content has been reviewed by the Medical Advisory Panel of Fighting Chance, which consists of seven highly regarded oncologists.

1. Power Point Slides. The core of the website is a booklet (sometimes referred to as a “deck”) of 44 Power Point slides -- and each addresses a different aspect of cancer. Here, for example, is one of the slides:

THE DISEASE

6. How It Spreads



Cancer transforms normal cells into cancer cells that then form a malignant tumor and also “metastasize” to form new tumors at other locations within the body.

From Cell to Cell

The first cancer cell in someone’s body started out as a seemingly normal cell that one day began mutating into a malignant cell -- over a period of several generations of cell division.



Cancer cell (in purple) after several cell divisions.



Once there are full-fledged cancer cells, they begin multiplying much more rapidly than normal cells -- as they divide in a haphazard manner. As a result, these cancer cells often pile up into a non-structured mass referred to as a malignant “tumor.”

From Place to Place

A malignant tumor can destroy the part of the body where it originated (the “primary site”) and then spread to other parts of the body where new tumors are created and even more destruction occurs. When a cancer moves from place to place like this, it is referred to as “metastasizing.”



Lymphoma
FDG PET scan in a lymphoma patient, including brain, chest and spleen involvement

Staging

Cancer patients often ask their doctor: “How advanced is my cancer?” The disease usually is described as being at one of four stages. For example, “Stage 1” means there is evidence of a tumor but only in the tissue of origin, whereas “Stage 4” means the cancer has metastasized to a secondary site, distant from the primary place it first occurred.

2. Curriculum. The Power Point slides begin with a Preface, which is followed by slides on eight distinct topics, and the book concludes with slides on key questions a more informed cancer patient would have in the dialogue with their doctor. Set forth below is an excerpt from the booklet which lays out the entire table of contents.

PREFACE

1. Frame of Reference
2. Author's Note
3. Historic Partnership
4. Fighting Side-by-Side

THE DISEASE

5. Where It Starts
6. How It Spreads
7. Why It's Harmful
8. Clue to the Cause -- Genetic Signatures

ODDS OF SURVIVAL

9. Every 20 Seconds...
10. Survival Rates Today
11. Long-Term Trends

WORKING ON A CURE

12. National Government
13. Specialized Medical Centers
14. The "Societies"
15. Big Pharma
16. "Smart Bombs"

TREATMENTS

17. Treatment Choices
18. Clinical Trials
19. Surgery
20. How Chemo Works
21. Side Effects
22. Damaged Atoms
23. Radiation Therapy

NEW DRUGS

24. Monoclonal Antibodies ("mabs")
25. "Big 3" Blockbuster Drugs
26. Drugs from Small Molecules

INSURANCE

27. Types of Coverage
28. Underinsured
29. Uninsured

COPING

30. Patient Empowerment
31. Oncology Social Workers
32. Cancer Patient Navigators
33. Help from Nonprofits
34. Community-Based Care

WHAT'S NEXT

35. It's Getting Expensive
36. Who Pays the Bill?
37. Better Testing

DOCTOR Q&A

38. Asking Better Questions
39. Are You and Oncologist?
40. My Type of Cancer?
41. Basis for My Diagnosis?
42. Has the Disease Progressed?
43. Are They Close to a Cure?
44. Can Someone Help Me Navigate?

3. Learning By Video. To augment the Powerpoint slides, the cancersimplified learning experience also incorporates brief videos – we call them “webisodes” – in which our patients talk about their own cancer journeys. These webisodes are easily accessed through a specific segment of the website.



Chapter 5

Genomic Testing, 2nd Opinions & Clinical Trials



In 2003 a group of scientists announced that they had identified the human genes perched upon the chromosomes that reside in the nucleus of every human cell. Every human, of course, has a genomic makeup that is utterly unique.

This breakthrough -- often referred to as “Genome Sequencing” -- led researchers to discover very specific genes that seem to be abnormal or “mutated.”

Further analysis showed that these mutated genes were often cancer-causing and, indeed, could be the primary driver behind many human cancers.

Within the last 10 years science has advanced to the point where specific mutated genes can tell us whether a specific cancer therapy will be effective.



A mutated and cancer-causing gene (BRCA1, in this artist's rendering) as if seen under an ultra high-powered microscope

Because a patient's “genetic signature” can have an impact on the type of drugs prescribed to treat his or her cancer -- especially “biologics” -- some type of genetic testing is now commonplace in many of the nation's largest hospitals. Indeed, a genetic analysis is among the first tests that most oncologists require.



Some of the tools used in genetic testing

On the East End of Long island the largest hospital is in Southampton. Because it has slightly fewer than 200 beds, it is known as a “community hospital” and lacks much of the complex equipment and testing abilities found at major cancer centers.

Fortunately, in 2016, Southampton Hospital merged with Stony Brook and that major medical complex made the facilities of its Cancer Center accessible to patients at the hospital in Southampton.

Since genetic testing begins by taking a simple blood sample, that sample can be sent from Southampton Hospital to Stony Brook, where a battery of tests -- looking for genetic mutations -- can be conducted. Results can then be conveyed to a patient’s oncologist on the East End who will integrate those findings in recommending therapeutic options.

Another option for East End cancer patients is traveling to New York City where they have access to some of the nation’s largest cancer centers, such as Memorial Sloan-Kettering or “MSK.” The MSK facility, for example, can provide genetic testing, second opinions, access to clinical trials and can provide an oncologist to serve as a patient’s primary cancer doctor.

2nd Opinions

Obtaining what is known as a “second opinion” is -- like genetic testing -- something that a cancer patient should explore before agreeing upon a recommended course of treatment from their oncologist.

While genetic testing often reveals whether a specific type of treatment will be effective, a second opinion -- if it is negative -- tells the patient that they simply do not have cancer. That conclusion is large part comes from a reexamination of what are called the “pathology slides.”

Another reason to seek a second opinion is if the patient's oncologist is not certain about the exact type of cancer or its stage of development. Greater certainty around these types of issues also can be helpful in recommending a treatment option.

On the East End of Long Island we often see patients who have selected a local oncologist, received a diagnosis and suggested course of treatment but seek a second opinion from oncologists at Stony Brook.

Two important items: (i) Most health insurance, including Medicare, covers the cost of obtaining a second opinion and the cost, in many cases, of genetic testing, and (ii) the oncologist initially treating a patient is rarely feels snubbed because a patient has sought another opinion from another source about the cancer diagnosis.

Clinical Trials

Only 3% of American adults with cancer decide to join a clinical trial -- although that percentage is increasing because today trials provide a means of priority access to extremely exciting new treatments such as "immunotherapy."

Clinical trials have several eligibility requirements and one of them often is that the patient has not yet received any other form of treatment (such as chemo therapy). Consequently the clinical trial option often is considered before the patient embraces therapy recommended by the oncologist because that therapy may exclude the patient from what could be a promising clinical trial.

During 2015 there were well over 200,000 clinical trials being conducted in the US and abroad to test the viability of new anticancer agents.

At Fighting Chance, we have a “Clinical Trials Advisory Service” headed up by a senior staff member and one of our directors who works part-time raising substantial funds for new cancer research. This team has developed a facility in searching for clinical trials using a couple of the data bases now available.

Sometimes the team at Fighting Chance can find a promising clinical trial more rapidly than the patient’s oncologist, simply because oncologists do not have the time to remain abreast of the vast clinical trials landscape.

Categories of Trials & Number of Participants

- **Phase I** (10-20) keeps escalating the dose of the new drug until the optimum level is reached. Sometimes remission is seen in a few patients: but everyone gets the same new drug.
- **Phase II** (100-500) To reach a Phase II trial the safety of the drug must be established and hence most patients in a Phase II trial receive the new drug; but the trial may also have a smaller group who receive the best current therapy (or in a few cases, merely a sugar pill).
- **Phase III** (1,000+) Participants receive either the new drug or the best standard therapy -- but now the new drug must prove its superiority in a vast audience of trial participants.



Health Insurance, Financial Issues & Patient Rights

The scope of health insurance coverage, for cancer treatment, depends upon several factors including the patient's age, income and whether he or she is employed by a company that offers healthcare benefits.

Most insurance covering the cost of treatments for cancer patients fall into one of four categories: Medicare, Medicaid, employer-provided insurance and policies taken out by individuals under the ACA, commonly known as Obamacare.

Medicare

Medicare is a form of healthcare insurance available to those age 65 or older (or to those who have certain disabilities). It is funded by the Federal Government with Part A free-of-charge, and Part B available on a modest-monthly-premium basis in most cases, while Part D also requires a modest premium payment.

1. Medicare Part A. Think of this as “hospital insurance.” It covers the costs of in-patient care in hospitals. It also covers a few other items like costs incurred at a skilled nursing facility, hospice and some in-home health care costs. Part A is most important when a patient's cancer is treated by surgery.

2. Medicare Part B. Think of this as “doctor insurance.” It covers, most importantly, the costs of all doctor visits and care. Part B is important because it covers a cancer patient's visits to the clinical oncologist, the radiation oncologist and other doctors that often are seen to help combat side effects of cancer treatments.

3. Medicare Part D. This is prescription drug coverage offered to everyone with Medicare. You need to affirmatively “sign up” for Part D and the plan is run by various government-approved vendors. You will pay a monthly premium and certain other costs. For cancer patients Part D is very important because they tend to be treated with both anti-cancer drugs and drugs which counteract negative side effects.

4. Coverage for Novel Agents & Clinical Trials. When new anti-cancer drugs successfully complete the clinical trial process and are approved for widespread public use, Medicare (as well as private sector insurers) may initially hesitate to cover the cost of these drugs. One reason is that these so-called “Novel Agents” often cost \$100,000 or more for a year of treatment. However, Medicare does cover virtually all the costs of a clinical trial.

Patient Copays

To discourage patients’ excessive use of the healthcare system most insurance policies -- whether from the government or private sector -- impose a “co-pay.” A simple example: the doctor’s bill is \$100. In that case the insurer will pay 80% and the patient has a co-pay obligation of 20% or twenty dollars. But the equation gets more complicated when the patient needs medications for newly-diagnosed cancer.

In a situation where the patient owes a 20% copay to the oncologist (for example, for an in-office chemo infusion) a “good faith effort” must be made by the oncologist to collect that amount. But many oncologists are not aggressive in their collection efforts.

Sometimes the copay can come from one of several charities set up to provide funding for that purpose. One of these charities -- and one of the most highly regarded -- is Cancer Care CoPayment Assistance Foundation (ph: 866-552-0729; information@cancer-carecopay.org)

Medicaid

There are millions of Americans -- and thousands on the East End of Long Island -- who do not have an employer-sponsored group health insurance plan, have not obtained health insurance on an individual basis and have not reached the age of 65 when Medicare coverage becomes available.

What happens when someone like this is diagnosed with cancer? If a patient has limited funds, often the answer is to help him or her promptly enroll in “Medicaid” -- which provides coverage akin to Medicare except the program is partly funded by the State.

1. Enrollment. If you desire the benefits of the Medicaid Health Insurance Program, then you will need to complete an application form and have it accepted by the Medicaid authorities -- at which point you will become enrolled. You can get help with this paperwork from the Patient Navigator at Fighting Chance

2. Where to go to Enroll. Across New York State there are many “Community Medicaid Offices” where you can obtain and submit an application form. For those living on the East End the nearest location is: Nassau-Suffolk Hospital Councils Facilitated Enrollment Program, 383 Veterans Memorial Hwy., Hauppauge, New York 11788 631.656.9783

3. Hotlines. You can always call the Dept. of Social Services in Hauppauge (Ph # 631.853.8730). A second helpline is the New York State Cancer Services Program (Ph # 866.442.2262). A third helpline is the New York State’s Medicaid Program Contact (Ph # 800.541.2831).

4. Qualifying Under “Needs-Based Test.” Be mindful that Medicaid benefits are intended for New York residents who are living at or near the so-called “poverty level”. Therefore, if you apply for Medicaid there will be an inquiry about your annual income and a test to see if it falls below a specified level that would qualify you for Medicaid coverage.

5. Scope of Coverage. For Medicaid-qualifying cancer patients this includes most surgeries, chemotherapy, radiation, and most prescribed drugs. For more information consult “NY Health Access” (www.nyhealthaccess.org).

Employer-Provided Healthcare Insurance

The most common form of healthcare insurance on the East End of Long Island is coverage provided by employers, large and small.

If you are diagnosed with cancer, and believe that your company has a managed care plan, we suggest you get a copy and review it -- because there several different types of managed care plans.

1. Health Maintenance Organizations or “HMO’s.”

These plans usually cover most expenses, but there is a small co-pay. What is more important is that HMO plans often limit your choice of providers to those within the specific HMO provider network. If you go “out-of-network” the patient may have to pay himself. This feature can be troublesome if a cancer patient identifies an exceptional oncologist who is not in the HMO network.

2. Point-of-Service Plans or “POS.” These offer the patient more flexibility than an HMO because they will often pay most of the costs of using a doctor “out-of-network” so long as doing so has been recommended by the primary care physician who is part of the POS.

3. Preferred Provider Organization or “PPO.” This plan is similar to an HMO in that it covers most of the cost of doctors within the preferred provider network. But unlike an HMO, a patient in a PPO plan can go to doctors outside the network (and do so without the need of a referral from his primary care physician); if patients take this step, however, note that the PPO will only absorb some of the cost of seeing that out-of-network doctor.

The common denominator with all types of managed care plans is the scope of coverage. Cancer patients can expect coverage for the diagnostic process, for surgery, for chemotherapy and radiation. In the case of Novel Agents -- especially those costing \$100,000 a year or more -- a patient should carefully investigate whether coverage is provided.

“Obamacare”

There is a large group of adults on the East End who fit the following profile:

- Their employment does not come with employer provided healthcare insurance.
- Their annual income is sizeable enough that they would not qualify for health care coverage under Medicaid.
- They are under the age of 65 and hence are not covered by Medicare.

It is this group of individuals who need to obtain health care insurance on their own, or risk living without any such insurance. And it is this group of individuals whose coverage options are directly impacted by the Affordable Care Act, commonly known as “Obamacare.”

New York is one of states that decided to implement Obamacare through establishing an “Insurance Exchange.” Consumers -- in this case individuals -- are supposed to shop on this exchange for a plan that is suited to their needs; coverage in the New York Exchange can be provided by several different private sector insurance companies.

It has been widely reported that consumers in New York are not completely satisfied with coverage under Obamacare -- the major complaints being high deductibles and sizeable annual increases in the premiums to be paid.

But in terms of the scope of coverage for cancer patients, Obamacare provides most of what would be seen with Medicare coverage or an employer-provided plan.

Financial Aid from Fighting Chance

If a cancer patient is receiving regular counseling at Fighting Chance he or she may qualify for a grant of up to \$500 for a wide range of emergencies.

— **Important Legal Rights for Cancer Patients** —

Apart from funding Medicare, the Federal Government has enacted several laws in the past few decades that protect important rights relevant to cancer patients and relevant, of course, to Americans suffering with many other types of diseases.

1. Family & Medical Leave Act (the “FMLA”). When someone is diagnosed with cancer and realizes that his treatment will force him to take a leave from his job, at least for a few weeks, he wonders whether he will get that job back once treatment is concluded. Being assured of the same job, when he returns from treatment, is guaranteed by the FMLA.

2. Health Insurance Portability and Accountability Act (“HIPPA”). This 1996 legislation established several types of patient protection; for example, if patients return to the workplace, the job they receive and the way they are treated cannot constitute “discrimination” -- a feeling that cancer patients sometimes complain of when they go back to work after a period of extended therapy.

3. Consolidated Omnibus Budget Reconciliation Act (“COBRA”). When someone loses a job that has included a group health insurance plan as a job benefit, he is understandably concerned about what coverage he will have during the period that they are looking for a new job. This concern is especially acute if someone loses a job shortly after a cancer diagnosis. COBRA allows someone to purchase comparable insurance (at the group insurance rate) for up to 18 months following their discharge so that, in most cases, there is no “gap” in insurance coverage.

4. Americans With Disability Act (“ADA”). Sometimes when cancer patients return to work there may be a transitional period when they are not fully ambulatory, but instead must get about in a wheelchair. The ADA prohibits any discrimination -- including specifically, workplace-centered discrimination -- that is based on this or many other types of physical disability.

Financial Issues

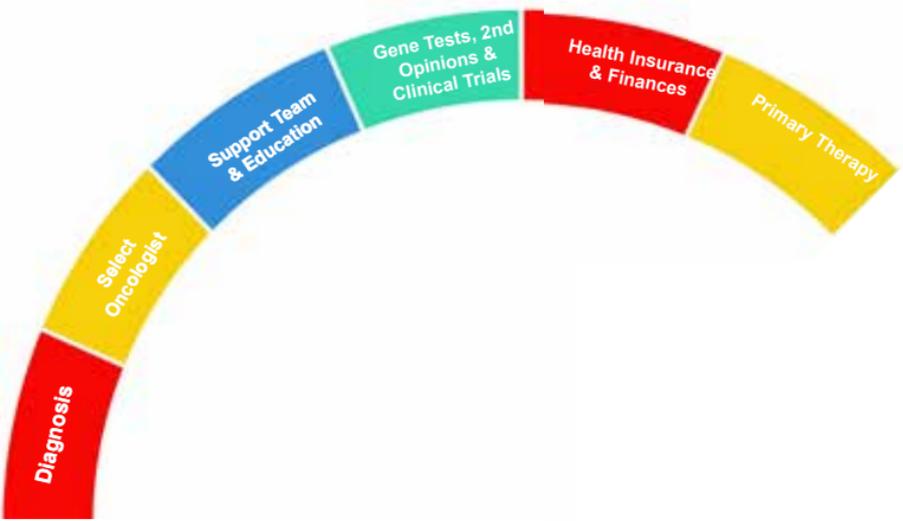
1. Develop a Financial Plan. This plan -- which is worth writing down -- should be worked on by the patient with assistance from someone on the Support Team, and, if possible an accountant or financial advisor. Assistance from counselors at Fighting Chance also is available.

The objective of a financial plan, simply stated, is to see if the patient has the financial resources to pay for the cancer treatment that lies ahead and is able to pay for the cost of daily living even if several weeks of therapy results in a temporary loss of their paycheck.

A patient is ready to craft a plan once three items have been clarified:

- **Type of Primary Therapy.** This will impact on whether the patient will need to take time off from work and if their leave of absence is unpaid then that has obvious consequences for financial planning.
- **Scope of Insurance Coverage.** As already discussed, most types of insurance cover the major treatment costs faced by cancer patients -- such as surgery, chemo and radiation. But this is an area that deserves careful analysis especially if there are major “copays” or treatment involves a novel agent not covered by any type of insurance.
- **Impact on Day-to-Day Living Expenses.** Newly - diagnosed patients often do not appreciate how the cost of daily living can be disrupted and often increased by the demands of cancer therapy. For example, if the patient requires a home health aid, that cost generally is not covered by any form of insurance and hence becomes a new financial burden in calculating weekly living expenses.

You're Almost There . . .





Several events have to occur before a cancer patient needs to decide upon a course of primary therapy.

First of all, they will have selected an oncologist -- and cancer care is best coordinated by a clinical oncologist. In addition, they will have received details about their diagnosis -- including where the cancer is located, the size of the tumor and whether the cancer has spread to additional locations.

Many patients also will have obtained a “second opinion” about their diagnosis and receive some form of genetic testing.

About 25% of newly diagnosed cancer patients are eligible for surgery as their initial therapy. These patients typically have “Stage 1” disease -- typically a small tumor in an organ such as the breast or lung which can be readily resected (meaning removed). After the surgery patients sometimes have additional treatment (also called “adjuvant”) such as an extended course of radiation.

Surgery is not an option for many cancer patients, and instead they embark upon an extended course of chemotherapy, often combined with radiation.

The “Stages” in a Cancer Diagnosis

Stage 1 -- in reference to a “solid state” tumor (for example in the breast, lung, or colon) the tumor is confined to the organ where it originated.

Stage 2 & 3 -- the tumor has become more sizeable and it has metastasized (meaning spread) to other areas of the body, with particular concern for implicating lymph nodes.

Stage 4 -- the spread of the cancer is now more pervasive and it typically has colonized into multiple organs in an aggressive way.

The initial or primary therapy does not always put a patient's cancer into remission, and thus many patients face a "2nd line" therapy -- meaning another drug that may be more effective against their cancer than the first.

For cancer patients on the East End the venue for their treatment and logistics, such as transportation, will largely be determined by their choice of primary therapy.

For example, if a tumor is to be removed from a female's breast, in a "lumpectomy" procedure, that surgery can, and often is performed at Southampton Hospital. Indeed, the facility includes an entire wing known as the "Ellen Hermanson Breast Center." This addition to the hospital was underwritten by proceeds from the annual "Ellen's Run," a beloved summer fundraiser.

There are other surgical procedures that are performed using complex and expensive equipment the Stony Brook Cancer Center. For example, if a man's prostate is cancerous, one of the most effective ways of removing it is a form of robotic-assisted surgery known as the "Cyberknife."

If the patient's primary therapy is chemotherapy-based, the chemo infusion can take place in an oncologist's office, and there are several such offices on the East End, which also helps to reduce the burden of transportation.

Many cancer patients -- either as their primary therapy, or as treatment adjuvant to other therapy -- receive radiation. In some cases the radiation treatments take place five days a week for several weeks in a row.

At present the closest radiation sites are in Riverhead. So, imagine a cancer patient who requires radiation but lives in East Hampton. He or she would be looking at a 45 minute commute to the radiation venue, and another 45 minutes to get home -- Monday through Friday for several consecutive weeks.

Many cancer patients desperately need transportation assistance. One place it can be found is at Fighting Chance, which has “volunteer drivers” on the road most days of the week.

Before their cancer journey is over, many patients switch the venue for their treatments -- typically from Southampton Hospital to a major New York City complex such as Memorial Sloan-Kettering. In the process, the patients also change their lead oncologist.

What are the reasons for this sort of switch? To begin with a patient’s initial therapy may fail to put the cancer into remission. So the patient will try to obtain a new drug -- known as “2nd line” therapy -- maybe a novel agent only available at a few of the country’s largest cancer centers.

Another example would be the failure of multiple drug-based protocols, leaving the patient with a complex surgical procedure as the only viable alternative. An example would be the treatment of multiple myeloma through what is known as a “stem cell transplant.”

Side Effects & Additional Treatment



Chemotherapy tends to be singled out as the anti-cancer treatment that produces the most pervasive negative side effects, although adverse side effects also can be expected from surgery, radiation and biologic/targeted therapies.

One of the themes of this guide is that having a strategy for the cancer journey helps the patient anticipate challenges before they are confronted and, where possible, prepare for them. No where is this principle more important than in the area of side effects, including the following:

1. Fatigue. This is the most pervasive negative side effect of all -- with several studies showing that about 90% of cancer patients experience mild to severe fatigue at some point during treatment. Science still has not decided how much of this fatigue comes from the disease itself as opposed to treatments such as radiation.

Fatigue caused by anemia and low thyroid function can be treated with antidotes. For other types of cancer-related fatigue, exercise can provide relief. There are also medications that make it easier to sleep.

2. Nausea. This is another commonplace negative side effect caused by chemotherapy. There are, however, several effective anti-nausea drugs available for cancer patients. It is fair to say that medicine has made significant strides in recent years to reduce nausea-related problems faced by cancer patients.

3. Pain. Some level of pain accompanies almost every type of cancer therapy. Pain is most intense, however, when the cancer begins to spread to multiple areas within the body. Imagine, for example, a tumor that begins growing within a bone, pressing out on an almost immovable barrier.

In recent years, fortunately, far more physicians have specialized in “palliative care” -- which essentially means pain management. Morphine is still a foundational medicine for cancer-related pain, but it comes in many variations from morphine drip to morphine patches. Advances have also been made to relieve symptoms caused by morphine use, especially the issue of constipation.

4. Other Negative Side Effects. Apart from those already discussed, patients should be prepared to potentially encounter the issue of anemia (which is a drop in the level of red blood cells that can result in intense fatigue), and neuropathy, which can produce a painful tingling in a patient’s extremities and can make walking difficult.

**When Side Effects Intensify
and Emergency Attention is Needed.**

While many cancer patients on the East End also have their clinical oncologist located in the same area, some patients are receiving their primary treatment at places like Stony Brook or even at a New York City facility. What do those patients do when some side effect becomes unbearable?

In most cases these patients go immediately to the Emergency Room at Southampton Hospital or to one of the local “Urgent Care” facilities on the East End.

The attending physician, of course, will seek information about the patient’s type of cancer, its stage and medications being used. This illustrates the importance of having a “team” with a family caregiver since they often can join the patient in the emergency room and have the presence of mind to keep track of medications and other details helpful in delivering emergency care.

During the course of their cancer journey, many patients hear the phrase “Second Line Therapy” which oncologists abbreviate as “2 L.” This refers to a situation where the initial therapy prescribed for the patient -- for example, chemo with particular cocktail ingredients -- has not proven “durable” in placing cancer into remission on a long-term basis.

In these situations the oncologist typically prescribes another type of drug or new drug combination. In many cases this second line treatment is effective and that successfully concludes the main therapy of the cancer journey.

But what if the second line therapy fails? Often the patient still has options. For example, they could consider a clinical trial testing a new experimental drug. For some cancers there are so many drugs emerging that one or more could be deployed in Third Line Therapy or “3L.”

Finally, with some cancers, such as multiple myeloma, a surgical solution may be available in the form of a stem cell transplant.

For cancer patients on the East End these options may be available by traveling to Stony Brook or to a large cancer facility in New York.





The last segment in the cancer journey is survivorship -- at least for patients whose cancer is placed into remission as a result of successful primary therapy. The time between diagnosis and completion of primary therapy, if all proceeds smoothly, is about one year.

Reaching the survivorship milestone, for a patient, is significant in many ways.

First of all, there typically is a feeling of great relief; patients often speak about “getting my life back.” Along with this come feelings of great elation and special events of celebration.

But survivorship over the long term -- meaning living without cancer for a decade or more -- requires careful planning. Think of it as a “survivorship plan.” It is prepared by the patient, but also with expert input from doctors as well as counselors at Fighting Chance, if the patient has been receiving supportive care from our charity.

When Fighting Chance helps a patient prepare a Survivorship Plan we recommend that it include six sections, as follows:

1. **Medical History.** Within a few months of reaching the survivorship milestone, many patients simply forget the treatments they endured. Before forgetfulness sets in, a patient should work with the doctor on a summary of the treatments received. In the case of chemo therapy, for example, you should record the ingredients of the “chemo cocktail,” the frequency of infusion and any side effects suffered.
2. **Medical Tests.** There is a very sizeable amount of data that is accumulated about a patient’s disease -- as the result of tests performed in order to make the cancer diagnosis and tests required during the course of therapy, such as blood work, CT scans, biopsies and

MRIs. If possible this data should be captured as part of the Survivorship Plan.

Once a patient's cancer is placed into remission, the patient typically undergoes tests -- at least once a year -- to be sure that the cancer has not returned. There could be other tests also required on a periodic basis. The schedule of these tests, going forward, also should be reflected in the Survivorship Plan.

3. **The Immune System.** Over 65% of cancer patients receive some form of chemo therapy as part of their treatment regime. One of the prime side effects of chemo is a degrading of the patient's immune system, making him or her more susceptible to infections. Understanding this vulnerability and developing strategies to deal with it also should be part of the Survivorship Plan.

4. **Potential Long-Term Medical Issues.** There are a handful of side effects from cancer therapy that can be long-lasting -- meaning they may burden the patient for many months, if not years. For example:

- **Neuropathy.** This is a form of nerve damage that can result in an irritating tingling in the toes and fingertips and sometimes leave the patient with a kind of "gimpy foot" which leads to an unsteady gait when walking.
- **Chemo Brain.** Chemo treatment often results in cognitive degradation, which usually lasts for a few weeks after treatment has concluded. This condition, commonly known as "Chemo Brain" can leave the patient with temporary memory lapses and the inability to reason through complex issues.
- **Lymphedema.** This refers to a build up of fluid in the body as a result of removing numerous lymph nodes that were compromised by being colonized by cancer from the patient's primary tumor site. The condition produces swelling in arms and legs and can be alleviated by special massage techniques.

5 Coping With Maintenance Therapy. After a patient's cancer is placed into remission his or her oncologist sometimes recommends "Maintenance Therapy." This takes the form of extended use of chemo for many months, if not years. The objective is to suppress the potential return of cancer. One of the most common forms of maintenance therapy is the use of Tamoxifen by breast cancer survivors.

6. Stress Management & Strategies Like Yoga. In thinking about survivorship, the patient should appreciate that there will be strains and adjustments to normal life and considerable stress. There are many options for reducing such stress, but at Fighting Chance we often recommend yoga and we run free yoga classes on a weekly basis, at multiple locations on the East End.

Author's Notes

This pamphlet is known around the Fighting Chance office as the “Blue Guide.” It has a companion which is known as the “Orange Guide.” If you are someone coping with cancer on the East End of Long Island, I suggest you read both guides because they are intended to be complimentary.

This Blue Guide is entitled, “Tips & Strategies” and reflects 15 years of accumulated wisdom, on the part of myself and our staff, regarding precisely how the “cancer journey” unfolds and ways to avoid unexpected surprises.

Meanwhile, The Orange Guide is a where-to-find-it resource directory that puts empowering and actionable information into the hands of cancer patients searching for ways to cope with the disease..

The first time Fighting Chance prepared a guide for cancer patients was in 2003 -- about a year after our charity started. Since then the guide has been revised on several occasions as we have accumulated evermore wisdom about the disease through counseling over 2,500 cancer patients.

As the author of the very first guide in 2003, and subsequent revisions, and as the author of both the Orange Guide and Blue Guide, I am deeply indebted to Charles Grubb, a gifted graphic artist. I have spent hundreds of hours at Charlie's elbow, in his Bridgehampton studio, and these guides would not have been possible without his dedicated collaboration.

*Sag Harbor, NY
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