

FIGHTING CHANCE

The Cancer Journey:
Step-By-Step

*www.fightingchance.org
Sag Harbor Office: 631.725.4646
Southampton Office: 631.638.7400*

Welcome

Over 15 years ago my mother, who lived in Sag Harbor, was diagnosed with lung cancer. She lived for another 100 days.



Duncan Darrow
Founder & Chairman

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

We also needed an expert to help navigate the healthcare system which was overwhelming us with red tape. And we needed professional counselors who could help us overcome the feelings of hyper-anxiety. Back then there was no place to go.

Now there is: Fighting Chance

Accreditation



In 1951 the American Medical Association established the “Joint Commission” as a non-profit that would audit healthcare facilities once every 3 years and “accredit” them if they met the highest standards of patient care.

Fighting Chance is the only cancer counseling center in the United States to have sought and obtain such accreditation, a process which included a 3 day on site visit to interview staff and review all office procedures.

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Introduction



Fighting Chance is America's oldest and largest free Cancer Counseling Center which operates on a regional basis and is accredited by the Joint Commission.

In our case the regional focus is the East End of Long Island.

Fighting Chance has two offices: our office in Sag Harbor (at #34 Bay Street) which we have occupied for a decade, and a second office opened in early 2019 within the Phillips Family Cancer Center in Southampton

Both offices are staffed by highly credentialed professionals including: oncology social workers, clinical psychologists, and certified cancer patient navigators. All of their counseling services, and all other support we provide, is free-of-charge.

Our counselors typically meet with a cancer patient once a week for two months. The main concern is helping patients cope with two overwhelming fears and manage the stress and hyper-anxiety those fears produce..

First of all, many patients view a cancer diagnosis as a death sentence. They are afraid they are going to die, afraid the dying process will be painful and afraid that their family unit will be disrupted.

Second, patients are fearful of battling cancer. They realize it is a journey, but one into the unknown. In these cases, part of our job at Fighting Chance is to explain the journey, step-by-step, so patients feel there will be very little which is unexpected. They take comfort in the fact that we have navigated cancer journeys for over 2,000 patients during the past 18 years.

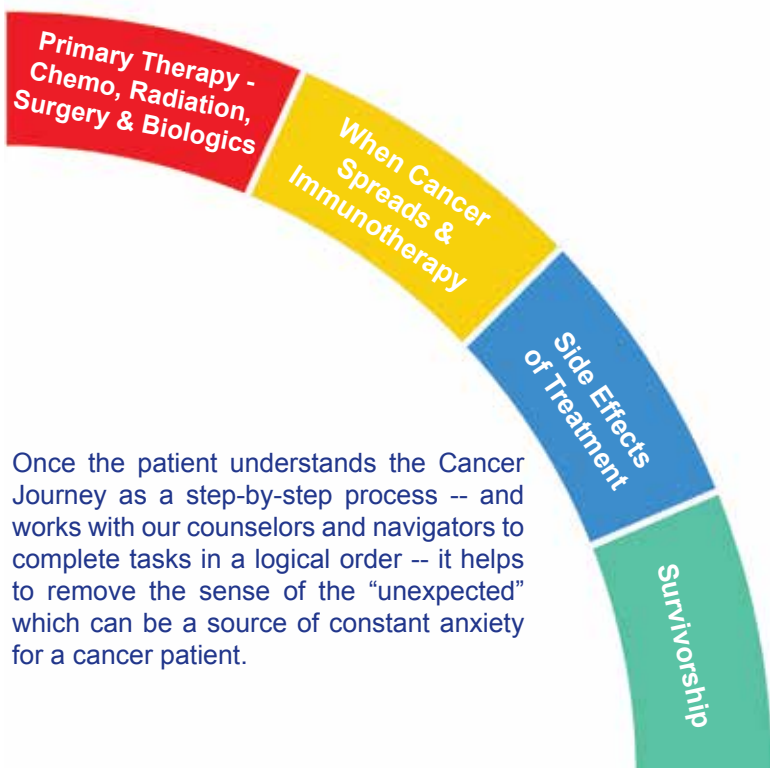


The “Arc” of the Cancer Journey

At Fighting Chance we counsel our patients to think of their battle with cancer as a “journey.”

There is an “arc” or trajectory to the journey. Patients see themselves as moving along that trajectory on a step-by-step basis and we monitor their progress to ensure that they do not take on tasks out of sequence or before they are fully prepared.





Once the patient understands the Cancer Journey as a step-by-step process -- and works with our counselors and navigators to complete tasks in a logical order -- it helps to remove the sense of the “unexpected” which can be a source of constant anxiety for a cancer patient.



Group Counseling Room at our Sag Harbor office



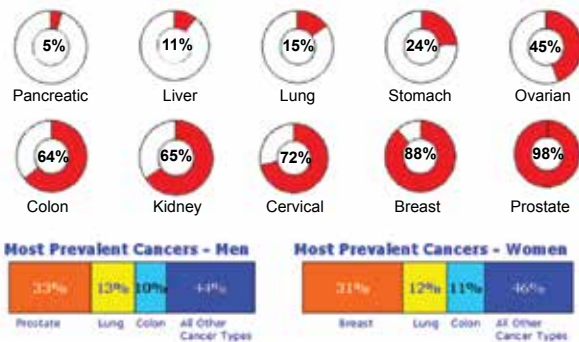
Our new office at The Phillips Family Cancer Center



If there is a suspicion someone has cancer, then there are several diagnostic steps physicians will take to see if the existence of a malignancy can be confirmed

Tumor Location

If a malignant tumor is suspected, then the physician's first task is to figure out the tumor's location, also known as the tumor's primary site. One of the reasons this is important is because five year survival rates vary depending on the organ in which the cancer is based. These are survival rates for several types of cancer (averaging out the different stages at which the disease was diagnosed).



All of these cancers present as a “solid state tumor.” However, about 15% of all cancers are “liquid cancers” and examples include: leukemia, lymphoma and multiple myeloma.

* Source of Survival Rate Data: multiple scholarly articles

Testing for Cancer

For solid state tumors there are five tests that are considered essential in developing a cancer diagnosis, and it typically takes at least a week or two to complete them. They are:

- **Blood Tests.** The physician is looking for suspicious “biomarkers” in the blood that could only derive from cancer cells.
- **CT Scan.** A “three-dimensional” X-ray that reveals various types of suspicious mass which could be a tumor.
- **MRI.** Another powerful imaging tool which uses magnets and radio waves to produce detailed pictures of organs and tissue.
- **PET Scan.** When a sugar-based fluid is injected into the patient, cancer cells will find it “magnetic” thus revealing their mass and location.
- **Biopsy.** Involves taking a small tissue sample from the suspected tumor site and having it examined microscopically by a pathologist.

Staging

When a patient is told that they have cancer, they also should be told about the stage of the disease, which refers to how far advanced the cancer is. For solid state tumors there are four stages:

- Stage 1.** The cancer is confined to the organ in which the tumor originated.
- Stage 2.** The cancer has spread from the primary tumor to adjacent lymph nodes.
- Stage 3.** The cancer has now colonized into other organs.
- Stage 4.** The spread of the cancer is pervasive and its metastasizing is robust.



Selecting an Oncologist & Patient Education

During the course of the cancer journey a patient may be treated by several different types of oncologists, including those who perform surgery and oversee radiation treatments.

But, there needs to be one oncologist who is “first among equals” and serves as the “quarterback” for devising the patient’s treatment plan and overseeing its implementation. In almost all cases this leadership position will be filled by a clinical oncologist. And the patient will lean on them heavily for expertise and even moral support.

Now that the Phillips Family Cancer Center has opened there should be multiple clinical oncologists within the Center who can lead a patient’s battle against cancer. An added benefit is that the oncologist will have ready access to the extraordinary resources of the larger Stony Brook healthcare system -- including its hospital, medical school faculty and scores of laboratory research scientists.

There is another group of clinical oncologists, on the East End, who operate out of the facility in Southampton known as the New York Cancer & Blood Specialists, or “NYCB.”

Many refer to this as a “Chemo Clinic” because its preferred form of treatment is chemotherapy and facilities for radiation oncology are not on site. This is an important “missing link” because a majority of patients who are treated with chemo also need to be treated with radiation. Indeed both treatments are linked together in what is known as “chemo-radiation.”

Education & Empowerment

Many patients come to Fighting Chance with an overwhelming sense of helplessness and -- if we are doing our job -- they should conclude their Fighting Chance experience with a renewed sense of empowerment.

One of the most important tools for a patient in search of a sense of empowerment is gaining a better education and understanding about cancer as a disease. A few years ago we developed a web-based learning system which is incorporated into our internet site. It is known as "cancersimplified" and consists of 44 PowerPoint slides. Here is the table of contents.

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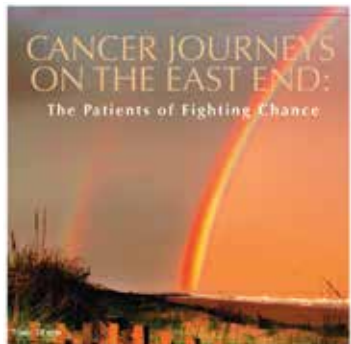
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Learning By Video. Our web-based learning system also includes brief videos in which our patients talk about their own cancer journeys. Here's an example:





Genetic Tests & Clinical Trials

Within everyone cell in your body is your unique “DNA” -- a bundle of thousands of genes that serve as the “blueprint” for your appearance and the development of every element within your body. No two individuals have the same DNA.

Cells that become cancerous also have DNA inside them and analyzing the DNA’s genes -- in a process called “genetic testing” -- is an important step preliminary to devising the best treatment for a cancer patient.

When genes are given closer examination, science often finds that a few of them are “mutated” and science believes these rogue genes are what causes cancer in many cases.

More importantly, some genetic abnormalities will make cancer cells more susceptible to an anti-cancer drug, while other genetic mutations can thwart the effectiveness of an anti-cancer therapy.

Clinical Trials

The phrase “Clinical Trials” refers to a process -- highly regulated by the Federal Government -- in which experimental new cancer drugs are tested on human subjects, after first being tested on mice.

At first the human trials are small -- less than ten patients -- since science is unsure about the safety of the new drug. If the drug proves safe in its “Phase 1” Trial then larger groups of patients can receive the drug in what are known “Phase 2” and “Phase 3” Trials. At the end of this process some drugs are approved by the FDA for widespread use.

Only 3% of US adults with cancer opt to take part in a clinical trial -- mainly because the safety and effectiveness of the drug being tested is viewed as uncertain.

But clinical trials become a more compelling option if a patient's cancer is "late stage" and the therapies already tried have been unsuccessful.

The pipeline of anti-cancer drugs now in clinical trials is over 1,000. And most trials are only conducted at the very largest and most prestigious cancer centers. Fortunately, Stony Brook is one of them, and at any time it could be overseeing well over 100 trials of new anti-cancer drugs.



Depiction of scores of genes perched on branches of the DNA double helix.



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

Stress Management & Health Insurance



During the cancer journey it is critically important that the patient moves forward in a logical step-by-step process. If the patient tries to tackle an important issue in a way that is out of sequence, then issue resolution will be much more difficult and even counterproductive.

A good example of proceeding logically is illustrated by the issue of stress management and health insurance. Obviously a patient should not plunge into cancer therapy without a game plan to manage stress -- since the therapy (and its side-effects) almost certainly will be highly stressful.

Cancer treatment also can be expensive and hence it is logical to pin down the scope of a patient's health insurance before launching into treatments for which the patient might be financially responsible.



Stress

On a psychological level almost anyone with cancer experiences it as an assault on their sense of well-being and peace of mind.

Some view cancer as a death sentence; others are less pessimistic, but they still realize that their lives will be plunged into uncertainty and disrupted by endless medical interventions.

Fear, hyper-anxiety, high blood pressure, sleeplessness -- they all converge to greatly elevate the patient's sense of stress. To make matters worse, it is widely accepted, as a scientific principle, that an elevated level of stress can degrade the effectiveness of the body's immune system. And a degraded immune system will make the battle against cancer more difficult.

Consequently, the counselors at Fighting Chance usually have extended discussion with our patients in an effort to devise a strategies for managing their stress -- and doing so before cancer treatment begins. This field of specialization is sometimes referred to a "psycho-oncology."

Medicare

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

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.

4. Coverage for Novel Agents & Clinical Trials. When new anti-cancer drugs are still in clinical trials Medicare will not cover the cost of the drugs nor the costs of trial participation.

Medicaid

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

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.

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.”

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; however 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

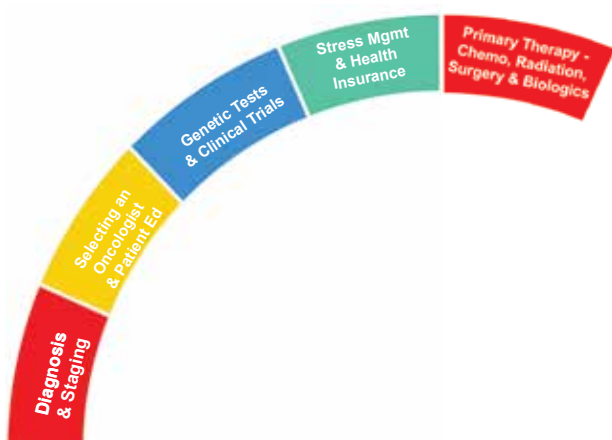
There is a large group of adults on the East End who fit the following profile:

- 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 and will be looking to secure coverage under Obamacare.

There is a wide variety of policies available from Obamacare and some would say the selection is bewildering. But for cancer patients the most important point is this: every version of Obamacare covers the vast majority of medical costs associated with most types of cancer therapeutics.

You're Almost There . . .





Primary Therapy -- Chemo, Radiation, Surgery & Biologics

The four most prevalent interventions, in the treatment of cancer, are:

Radiation	70%
Chemo	60%
Surgery	25%
Biologics (a/k/a “Targeted Therapies”)	15%

Chemotherapy

Among recently diagnosed cancer patients, a common assumption is that the backbone of their treatment will be chemo, and indeed, they may not need any other therapeutic intervention. That view is misguided.

In fact, there are very few cancers where chemotherapy is the only mode of treatment. It is far more likely for chemo to be prescribed in combination with other interventions. For example:

- Chemo can be deployed before surgery to shrink the size of the tumor and improve the odds of being able to remove it surgically (called “neoadjuvant” use).
- Chemo can be used after surgery to help suppress the possible recurrence of cancer (called “adjuvant” use).
- During the intervals between chemo cycles, radiation can be introduced since there is some evidence this makes the chemo more effective (called “chemo-radiation”).

** Source of Data on Therapeutic Usage: multiple scholarly articles*

When Radiation is Deployed

When oncologists speak about radiation they typically divide its use into two distinct categories.

First of all, there is “external beam” radiation. Here the patient is prone on a gurney and a sizeable piece of equipment hovers over them projecting a laser-like ray at a specific tumor site. Many different tumors are subjected to this form of radiation and treatment often continues, day-after-day, for several weeks. But radiation is a proven killer of cancer cells.

A second form of radiation involves implanting “seeds” inside the patient anatomy and next to a tumor site -- such as a cancerous prostate gland. Over a period of time the seeds emit radiation at close range and can leave the prostate cancer free.



A state of the art linear accelerator -- the radiation oncology equipment on site at The Phillips Family Cancer Center

The Surgical Option

When treating cancer, oncologists shy away from using the word “cure,” but surgery that removes an entire tumor -- especially if the cancer was detected early -- comes close to what many would consider curing cancer.

A good example is lung cancer which in recent years has been detected at an early stage thanks to the powerful imaging from CT scans. These scans increasingly reveal tumors that are “Stage 1” and they are candidates for removal using microsurgery. Sometimes no further treatment of any sort is needed.

Targeted Therapies

A “targeted therapy” as the term suggests only homes in on and seeks to destroy cells which are cancerous. That is quite different from chemotherapy, which is attracted to any cell with rapidly-growing characteristics. One such cell type is cancer. Human hair also is comprised of rapidly growing cells -- chemo kills them as well, which is why patients receiving chemo become bald.

There are about 50 targeted therapy drugs now approved for widespread use. But the ground-breaking drugs are three therapeutics discovered in Silicon Valley by a company known as Genentech (merged two years ago with Roche).

The Genentech drugs result from the combination of living organisms and are so complex the new molecular entity is “oversized” or sometimes called a “large molecule drug.”

The troika of drugs that Genentech pioneered include: Rituxan, Avastin and Herceptin. Their mechanism of action is illustrated below.

**Rituxan
(Rituximab)**
For:
Non-Hodgkins
Lymphoma



The Rituxan antibody binds to a cancer cell and labels it for destruction by the immune system killer cells.

**Avastin
(Bevacizumab)**
For:
Colon, Lung &
Breast Cancer

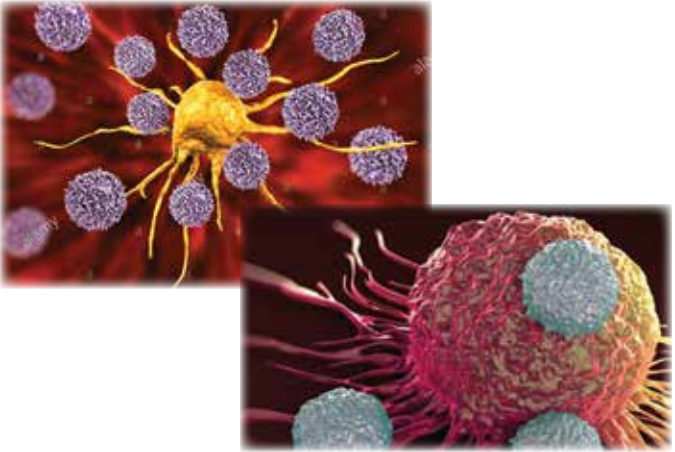


Avastin inhibits a growth factor for cancer (called “VEGF”) and that reduces blood supply to the tumor.

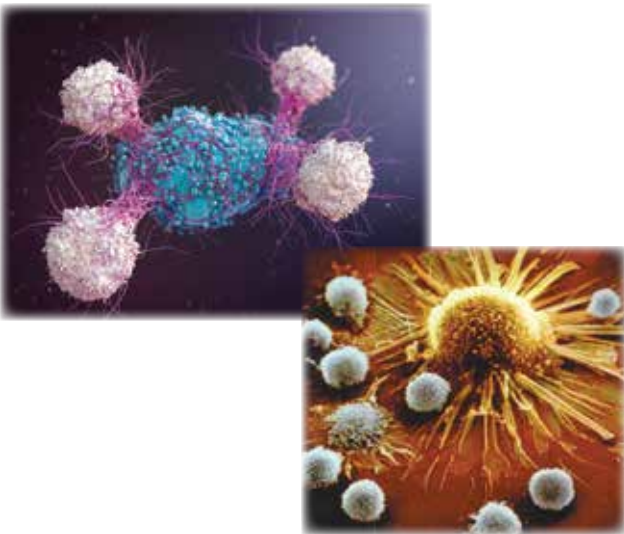
**Herceptin
(Trastuzumab)**
For:
Breast Cancer



The Herceptin antibody (is orange) restrains a cancer growth factor (in purple) from being activated by HER2 (in pink)



Ganging Up. All of these are images of T-cells going in for the kill on a cancer cell. The T-cells often -- as these images indicated -- gang up on a singular cancer cell and seemingly attack with the instincts of a wolf pack.



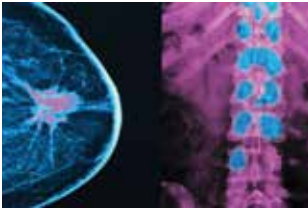


When Cancer Spreads & Immunotherapy

Metastatic Cancer

Among the 600,000 Americans who died of cancer in 2018, about 80% of them had the “metastatic” version of the disease, and that played a significant role in their downfall.

The term “metastatic” refers to cancer which has spread from the original tumor site to other organs and locales within the body.



A breast tumor is on the left of the image and highlighted in purple, and its metastatic spread to the patient's spine shows up in light blue.

The metastatic feature of cancer results from the fact that a handful of cancer cells “hive off” from the primary tumor and then enter the patient’s blood stream. Many of these cells essentially drown as they surge along the bloodstream. But some find a perch on another organ. Eventually a few more cells find the same perch and a colony -- really a new tumor -- is established.

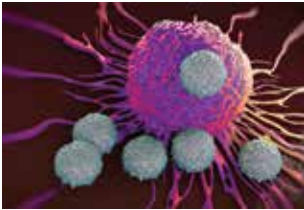
Science has been searching for decades for some type of drug that could counteract metastasis. The drug would have to be “holistic” and kill the patient’s cancer at the primary tumor site as well as any place else in the body where that cancer has migrated. Immunotherapy may represent a step towards such a “miracle drug.”

Immunotherapy

As of 2019 there are only a handful of immunotherapy drugs (often called “I/O”) that have been approved by the FDA for widespread usage. But many more I/O drugs are in the pipeline.

Most of the I/O drugs have the same underlying thesis. It begins with the fact that “T cells” -- the backbone of the immune system -- seem to have their effectiveness checked by some factor emitted from cancer cells just as the T cells are moving in for the kill. Science, simply stated, devised new drugs that inhibit that checkpoint phenomena. Indeed, the drugs fall into a new category called “checkpoint inhibitors.”

Examples include: Opdivo and Keytruda, both of which have shown remarkable results treating fairly advanced lung cancer.

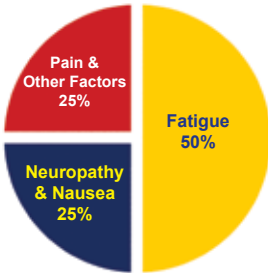


Use of an immunotherapy has inhibited the checkpoint against T cells and they now gang up for the kill against a cancer cell (in pink).



Side Effects of Treatment

Adverse Impact on Daily Life of Cancer Patients



Cancer fatigue is the #1 complaint of cancer patients in terms of something that interferes with their efforts to lead a normal life.

Deep-seated fatigue is widely acknowledged as a common result of both chemo and radiation therapy. As the most negative side effect of treatment, fatigue ranks #1 among half of all cancer patients in a recent and well regarded survey.*

The second most prevalent complaint is the nausea which is widely accepted as a consequence of chemotherapy.

Another side effect from chemo is the degradation of a patient's white blood cells and immune system. Here medicine offers a potent intervention, which is the drug known as Neulasta.

Finally, some patients with cancer -- especially if it has spread -- complain frequently about pain. The most acute pain, perhaps, results from the spread of cancer to the bone and skeletal system. These lesions can be reduced, to some extent, by radiation but they remain a crippling result of metastatic disease.





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. But survivorship over the long term requires careful planning. Think of it as a “survivorship plan.”

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 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 60% 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.



The first Saturday in June usually is a time when Survivor's Day is celebrated. Traditionally Fighting Chance hosts a free lunch for all survivors who wish to attend. It is held at Southampton Hospital and co-sponsored by the Hermanston Breast Health Center.

Survivors share anecdotes about their cancer journey, and the afternoon is a rewarding time for everyone.

Cancer Journeys on the East End -- was an award-winning video in 2009 and was favorably reviewed in the local press.

Cancer Journeys is our Flagship.... Six patients, in their own words, describe their battle with cancer – and all of them were successful. What they say is highly informative, easy to understand, and uplifting. (originally filmed for public television)



Journeys Part 1
10 minutes



Journeys Part 2
10 minutes

The Southampton Press

THE VIEW EAST

Giving East End Cancer Patients a Fighting Chance

By Reynolds Dodson

The thing about cancer is that it only happens to other people. That annoying ache in the ear, that little pain in the throat—that doesn't mean anything to you and me. But just suppose. Every year, 1,000 people on the East End get the kind of news no one wants to hear, and when that happens, it's devastating. Some years ago, it happened to Sag Harbor resident Charlotte Noble Selheim, who was diagnosed with lung cancer. Neither she nor her family knew where to turn. As Ms. Selheim's son, Duncan Darrow, a successful New York attorney, soon realized, it wasn't just the specter of mortality that was so horrible; it was the many details nobody ever thinks about: where to seek treatment, how to deal with the insurance company, who will pay the bills, who will cook the meals. At one point, Mr. Darrow said to himself, "All I ask is that my mother be given a fighting chance"— and that's when an idea was born. Fighting Chance, founded by Mr. Darrow, is now in its seventh year as the East End's only organi-

zation solely dedicated to helping cancer patients cope with all aspects of the disease. Headquartered in a welcoming Victorian on Route 114 in Sag Harbor, it has helped hundreds of frightened people through the labyrinthine maze of treatment, support and recovery. Next Thursday, July 9, at 8 p.m., SEA-TV in Southampton and LTV in East Hampton will carry the first documentary devoted to Fighting Chance. It's a 40-minute production called "Cancer Journeys on the East End: The Patients of Fighting Chance," and it should be viewed by anyone who wants to understand this illness. Far from being the "downer" you might expect, it's a stirring tribute to the human spirit made more poignant by its focus on real people living here on the East End. Recently, I talked to Ben Gillikin, Fighting Chance's vice chairman, and Maxa Luppi, a "patient navigator." Ben is a former cosmetics company executive who now lives in East Hampton, and Maxa is a Water Mill resident whose late husband, Dick, was a friend of mine. There are a lot of charities with good intentions, but Fighting Chance is unusual in its local focus

Appendix A



Videos of Interest from Fighting Chance



A unique educational resource for cancer patients -- on the Fighting Chance website -- is a collection of videos in which our patients speak about their cancer journeys.

FREE LEARNING

- Resource Directory
- Tips & Strategies
- Cancer Simplified
- Video Library

Men + Cancer

... listen in on the poignant and informative viewpoints shared by four men, all of whom are cancer survivors and have met monthly for years.



Men + Cancer
6 minutes

Voices from fighting Chance

... patients speak about the benefits they received from a free cancer counseling center on Long Island



Voices

8 minutes

Day of Hope

... an inspiring record of 300 cancer patients gathered together for one day to hear about life-saving scientific breakthroughs.



Day of Hope

9 minutes

Biography of Fighting Chance

... a slideshow history of the renown free cancer counseling center on the East End of Long Island



Bio

5 minutes



Local News Articles About Fighting Chance

THE EAST HAMPTON STAR

Thursday, July 29 2010

New Day and New Digs for Fighting Chance

Therapy dogs, benefit bash, and more outreach than ever



The staff of Fighting Chance gathered recently at the organization's new headquarters on Bay Street in Sag Harbor. photo: c.b. grubb

BY JENNIFER LANDES

1,000 to 1,500 people each year are diagnosed with some kind of cancer on the East End. Of those, 350 end up dying in hospice care within that year, according to Duncan Darrow, the founder and chairman of Fighting Chance in Sag Harbor.

The diagnosis, as one patient described it, "is like being struck by lightning." Mr. Darrow said he envisioned the service organization as a resource to answer the questions patients have within 48 hours of being told of their disease, and to let them know what services are available in an area somewhat remote from specialty health care.

He started the organization in a garage in 2002 after seeing the struggles his mother went through during treatment on the East End. He began with a vision for a guide to services, and as the years have passed he has continued with symposiums, Web site development, psychological support, targeted informational materials, and even practical support such as cleaning services and transportation.

And now the group has a bright and cozy new headquarters on Bay Street in Sag Harbor, with a library, conference area, and private meeting rooms all designed to be warm and welcoming to patients and caregivers dealing with trauma. A sold-out benefit for the group will be held on Saturday at the Wolfier Estate Vineyard in Sagaponack.

A large portion of those diagnosed with cancer on the South Fork find their way to Fighting Chance, where they are given free counseling and a variety of information

targeted to their disease and appropriate to their willingness and ability to absorb that information.

The oncology social workers include Karrie Robinson, who came out of retirement from Memorial Sloan-Kettering Cancer Center to help the organization as director of clinical programs, William De Scipio, a clinical psychologist, and Margaret Bromberg, an oncology social worker.

With few cancer specialists serving the area, the group strives to step in and help with questions regarding the illness and the effects of treatment, as well as holistic approaches to well-being. It is not linked with any of the East End hospitals, but Ms. Robinson said they have an informal relationship with them. "We know when one of our patients leaves the hospital" after treatment, for example, or when they go back in for more.

Hearing the concerns of patients firsthand has given the group a unique role in advocacy and in meeting needs such as patient literacy. Fighting Chance has joined an effort to change the way doctors speak to be more intelligible to those outside the field. Having three oncologists on its board makes these discussions easier to have.

On its own, it has devised a flip-chart booklet called "Cancer Simplified," which provides a 15-minute education in the basic biology of the illness, the cost of treatment, the types of treatment and the aftereffects, services available, questions to ask, and how to navigate it all. It is one of the first things given to Fighting Chance patients.



KARRI ZAMPINI ROBINSON, DUNCAN DARROW AND JANINE VETO

shaw photo

FIGHTING CHANCE

Organization Is a Life Saver

One year after opening, help thousands cope with cancer

BY RACHAEL SHAW

It is exactly one year since "Fighting Chance" opened up its office in a little alley off Main Street, Sag Harbor. Since then the charity, which is committed to providing support and information for cancer patients and caregivers, has grown remarkably.

The charity's story actually begins two years ago, in 2003, when Fighting Chance first came into existence. The first twelve months were spent preparing what Duncan Darrow, Fighting Chance's Chairman, describes as "a yellow pages for cancer care." This guide, "Coping with Cancer on the East End" is the focal point of Fighting Chance's efforts to provide support for cancer sufferers in the local community. Compiled with the help of members of the medical profession, it provides patients and caregivers with the necessary tools to find answers to all kinds of questions concerning cancer and the practical difficulties that are involved in its treatment.

"Fighting Chance realizes how important it is to have bridges with the medical community," says Darrow, and to this end, a Medical Advisory Committee has been set up with doctors and administrators from hospitals such as Southampton, Riverhead and Memorial Sloan Kettering. Janine Veto, Deputy Director of Fighting Chance says, "it's our job to build up doctor confidence in Fighting Chance, so they see our guide really can be a helpful part of patient counseling." Kerri Zampini Robinson has also come on board. Formerly Director of Post-Treatment at Memorial Sloan Kettering, Robinson offers a unique insight as an oncological social worker and will be a liaison with the Medical Advisory Committee. She praises the guide saying that, "it gives them [cancer patients and caregivers] what they need. It is relevant and informative."

Over the past year, Fighting Chance has seen its website "explode," now receiving over 4,000 hits every month.

Further evidence of the charity's success is provided by their recent partnership with Cancer Care, a national non-profit that provides free, professional services to people with cancer. The two organizations have co-published the new edition of the guide but Darrow says that there is more to the collaboration - "Cancer Care is a national organization. If we have a caller with a significant level of stress we can now refer them to Cancer Care to ensure that they receive the help they need."

"We're working with cancer patients at the grass roots level in Suffolk County," he said. "We know a lot about local resources because we sort of 'wrote the book' on that. So, out here, we can really help cancer patients map out the support system they need to improve their chances of survival."



THE TEAM: *Karris Robison, Duncan Darrow and Heather Matthews*

photo: John Bayles

5 Years of Giving A Fighting Chance

BY JOHN BAYLES

FIGHTING CHANCE has moved from a tiny space behind the Kramoris Gallery to a traditional, beautiful Sag Harbor home on the corner of Jermain Avenue and Route 114. They may have a swank new place, but they're not letting it go to their heads. Their mission remains the same — to provide help to those who need it most.

Fighting Chance was founded five years ago by Duncan Darrow and on Saturday, they will hold a ribbon cutting ceremony for their

new offices. Fighting Chance is growing into a non-profit that Darrow hopes will one day be synonymous with his hometown.

The name came from a prayer. In 2001 Darrow's mother was diagnosed with lung cancer.

"My brother and I ran around for five months trying to deal with the logistics," said Darrow. "Frankly I was pissed off."

"Dear God, all we're asking for is a fighting chance. That was my prayer every night," said Darrow.

Fighting Chance began as a

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, “The Cancer Journey: Step-by-Step.” It reflects 18 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 C.B. 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
March 1, 2019*

Duncan N. Darrow
*Principal Author and
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www.fightingchance.org



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