

# FIGHTING CHANCE

AUGUST 2014



## SPECIAL ISSUE: SURVIVORSHIP PLANS

### **From Patient to Survivor . . . Don't Get Lost in Transition**

When we opened Fighting Chance in 2002, we mostly provided free crisis-type counseling to patients who usually came to us within a week of their cancer diagnosis. They were often in a state of shock, and their #1 question was: "How can I possibly get through this?"

With help from our professional staff, most patients overcome their trauma-like symptoms and regain their composure and their confidence in decision-making about a course of treatment. At this stage most individuals see themselves as "patients" – immersed in medical treatment along with endless hospital visits – and are reluctant to identify themselves as "survivors." But everything changes once cancer is put into remission and a blood test shows that finally you are "cancer free."

### **Survivorship Plans**

Now a new chapter begins that commonly is known as "survivorship planning." It is an area of emerging importance among doctors and an area of growing expertise among the oncology social workers and clinical psychologists who staff our charity.

Our patients, increasingly, are asking how they can improve the odds of long-term survival since 40% of the 14 million Americans who are classified as cancer survivors have lived 10 years or more since their initial diagnosis. In the pages that follow we describe the types of issues that our staff considers as they help craft a survivorship plan for those we are counseling, always, of course, on a free-of-charge basis.



On June 1, 2014, Fighting Chance, in partnership with Southampton Hospital and its Women's Health Center, hosted a luncheon to celebrate National Cancer Survivors Day. There were over 100 survivors in attendance.

# Check List for a Cancer Survivorship Plan . . .

## 1 Priorities of a Survivorship Plan

✓**Medical** First and foremost there is a medical element to a Plan – steps the survivor should take to improve his or her odds of living a very long life and reducing the chances of a cancer recurrence.

✓**Psycho-Social** The treatments that put cancer into remission take a toll on both body and soul. Survivors often speak about “getting back to normal” – meaning life before cancer. But that means successfully coping with issues like stress and fatigue and creating the healthiest lifestyle possible.

✓**Educational** Learning more about the survivorship phase of the cancer journey can turn future events (especially medically-related) into something the patient anticipates, rather than being taken completely by surprise.

## 2 Who Can Help Draft a Survivorship Plan?

Rule # 1. The patient should not draft the plan alone. Get expert assistance if possible.

At Fighting Chance, for example, we have oncology social workers and a clinical psychologist who have helped many patients draft survivorship plans. Most patients at Fighting Chance have been seeing one of our staff for weeks on end, so when they reach the stage of needing a survivorship plan, they know someone who can help navigate the “next step” in their cancer journey.

The plan, by the way, can be as simple as a one-page “to do list” or it can be longer and more in-depth if the patient prefers.

Some parts of a survivorship plan require a doctor’s input, however. Perhaps the doctor best suited to that task is the patient’s clinical oncologist – who usually is the doctor who helped diagnose the patient’s cancer, helped develop a course of treatment and has seen the patient on multiple occasions.

## 3 Medical History

There are two basic parts to the medical component of a survivorship plan: a record of cancer treatments that already have occurred and a schedule of future testing.

As for medical history, it should include the type of cancer diagnosed, its stage, the organs involved and whether it metastasized.

If the patient had a surgical procedure or radiation treatment, that should also be described along with dates of treatment and physicians involved. If the patient had chemotherapy – and about 75% of all cancer patients do – a notation should be made about the specific combination of chemo drugs used, any side effects and any medications prescribed to combat those side effects.

This segment of the survivorship plan, ideally, should be reviewed by every physician involved in treating the patient’s cancer before it went into remission.

## 4 Medical Testing

During the survivorship journey, patients can also expect a series of periodic tests performed by doctors or nurses to monitor physical well-being and detect any recurrence of cancer at the earliest possible moment.

It is important to establish a clear schedule for these tests, which may take place annually or at other intervals. For most survivors the tests can include blood work, various types of “scans” (CT, MRI, and PET) and ultrasound.

## 5 Be Mindful of the Immune System

Extended chemo treatment can break down our immune system – a chemo side effect that patients sometimes do not appreciate. After initial drug treatment is successfully concluded, a patient needs time (often many months) to build the immune system back up. As one patient put it: “My immune system was reduced to a pilot light, and now I’m getting it back to a bonfire.”

## 6 Potential Long-Term Medical Issues

✓ **Nerve Damage.** In some cases the chemo drugs used to treat cancer do damage to a patient's nerve system, especially at the extremities . . . meaning the toes and fingertips. The resulting condition is known as "neuropathy."

A loss of sensation in the toes can leave a patient with a kind of "gimpy foot," making activities like jogging problematic. In the finger tips, neuropathy is often experienced as a tingling or even burning sensation and can be quite irritating, if not painful.

✓ **Chemo Brain** Chemotherapy treatment also can result in cognitive degradation – at least for a few weeks after treatment has concluded, but sometimes for many months. The condition is commonly referred to as "chemo brain" and can leave the patient with temporarily impaired memory or lapses in the ability to reason through complex issues.

✓ **Aftermath of Surgery** Some surgical procedures – for example, for breast cancer – often include removal of a tiny bean-shaped tissue known as the "lymph node." There are scores of lymph nodes in our body and the fluid that runs through the lymphatic system helps cleanse away waste material and helps us fight infection. When lymph nodes are surgically removed, however, there can be a fluid buildup that results in painful swelling in limbs such as the arms, and this can be a long-lasting condition.

## 7 Coping With Maintenance Therapy

After a patient's cancer is placed into remission, their oncologist sometimes recommends "maintenance therapy", which takes the form of extended use of chemo – for many months if not years. The objective is to suppress the potential return of cancer.

When a patient is on maintenance therapy his or her survivorship plan is more complex from a medical standpoint since he or she are regularly receiving powerful drugs that can have significant side effects.

## 8 Stress Management and Antidotes Like Yoga

In thinking about survivorship, the patient should appreciate that there will be strains in adjusting to a more normal life and there will be an almost daily fear that their cancer will return.

Whatever the source of stress, coping strategies should be carefully considered and can include yoga classes, peaceful mediation or counseling for occasional emotional distress from the professional staff at Fighting Chance.

In fact, Fighting Chance runs a weekly yoga session at Yoga Shanti in Sag Harbor (free of charge of course) and most of those attending are long-term cancer survivors.

## 9 Support Groups

At Fighting Chance our professional staff runs several support groups, most of which meet monthly. One of them is for patients who have completed initial therapy and are now facing the challenges of long-term survivorship.

What we have seen is that people want to share the experience of survivorship with others who are facing the survivorship phase of the cancer journey. They may come together for discussion or sometimes around an activity, but the central point is their common bond of having faced down cancer and lived to tell the tale.

## 10 Logistics Like Jobs and Insurance

Many cancer patients, once their disease transitions into remission, are highly energized and cannot wait to get back to work. But returning to the workforce full-time is a step-by-step process; especially because issues like deep fatigue can last grip the patient for months after primary therapy is over.

And if a survivorship plan envisions regular visits with the patient's doctor, the patient must determine if that type of medical care is covered by insurance? The answer today is that insurance will cover a few consultations over a survivorship plan, but most coverage has limits.

# Partnerships Forged with Fighting Chance



**Hampton Jitney in New Partnership to Support Transportation Needs of East End Cancer Patients Bus Tickets to New York City – for Specialized Care – Now Available at Fighting Chance Office**

Some of the 250 newly-diagnosed cancer patients we see each year would greatly benefit from a visit to a highly specialized oncologist in New York City – for a “second opinion” about treatment options or for other specialized care not available on the East End. But the cost of a round trip Jitney ticket for a patient and caregivers, gives them pause, understandably.

We recently explained these concerns to Geoff Lynch, who heads up the Hampton Jitney. Geoff’s immediate reaction was: “we can help.”

He suggested that the Jitney provide Fighting Chance

with packets of tickets and we would distribute them to qualified patients who called our office (631 725 4646) and came by to pick them up.

But we wanted to pay a modest percentage of the ticket costs so we turned to “crowd sourcing.” Via email, we asked our traditional donors, as well as Jitney riders, to chip in \$10 – sort of “micro-finance.” Scores of them did, and, within days the needed money was raised, and another free-of-charge service is now in place to support those battling cancer on the East End.



In December of this year, Wolfffer Estates Vineyard will host its 2nd Annual Festival of Wreaths, a Holiday Season event for the whole family. Money raised from the sale of wreaths decorated by local artists — goes to benefit Fighting Chance.



Over the past five years, Town & Country Realty has helped defray the cost of our summer Gala with a very generous donation.

The American Hotel in Sag Harbor has often donated a cruise on its yacht, as a top prize in the silent auction that is part of our Summer Gala. The lucky bidder gets a sunset spin around Peconic Bay for 10 guests and provides Fighting Chance with a generous gift.



Yoga Shanti has given Fighting Chance the use of its Sag Harbor studio for weekly yoga classes led by Eric Pettigrew, a yoga teacher who specializes in yoga for cancer survivors. Also attending is a member of our professional staff. Interested in attending? Call our office at 631 725 4646.



John Graham, who owns Hampton Racquet Club, is in the 2nd year of a summer tennis tournament that benefits Fighting Chance.



The Hamptons Swim Against Cancer put on through the combined efforts of the East Hampton Volunteer Ocean Rescue group and Swim Across America – is in its 6th year, with Fighting Chance as the main beneficiary.

This organization helps to connect East End businesses, that would like to support a worthy cause, with local non-profits that could benefit from such support. They were very helpful in nurturing the Jitney-Fighting Chance connection.



## FIGHTING CHANCE

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

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Or for information, please call our Sag Harbor office at 631 725 4646

[www.fightingchance.org](http://www.fightingchance.org)

