

**A**  
*Survivor's*  
**STORY**

By Tom Schaffner

**E**ight months before being diagnosed with Hodgkin's disease, 19-year-old Dan Shapiro traveled to England to visit the final resting place of his grandfather Edi. Shapiro's grandparents, Jewish immigrants who fled the terror of Nazi-controlled Austria in 1938, settled in England, only to be greeted by German bombs blanketing the British Isle. To make matters worse, the British government put Edi in a Scottish internment camp simply because he was a native of a German-influenced country.



# One man's battle with cancer and the lessons learned

A head injury to Shapiro's grandmother Ilse sustained during Nazi bombings brought about an early release of her husband Edi from the internment camp. As he had done his entire life, Edi continued to do whatever it took to provide for his family. But within a few years of the war's end, Edi had died of a lung disorder.

As Shapiro stood before Edi's grave, he placed his hand upon the headstone and wondered if he could be as resilient as his grandfather had been in the face of such adversity. Could he find that inner strength to continue? He thought not.

In 1987, Dan Shapiro was living the normal life of a 20 year old: two caring parents, a younger brother and a promising education from Vassar College in Poughkeepsie, N.Y.

But his life literally changed in April of that year. For four weeks, he had been experiencing shortness of breath, wheezing, night sweats, fever, chills, itching and nodal pain in the right shoulder whenever he consumed alcohol. A chest X-ray revealed a large tumor.

A CT scan showed a 14 cm mediastinal mass and palpable supraclavicular nodes. The tumor that started in his chest was wrapped around his trachea, making breathing difficult. Diagnosed with Stage IIB nodular sclerosing Hodgkin's disease, his doctor prescribed a combination of chemotherapy and radiation therapy over the next seven months.

Concerned about the nausea and vomiting side effects of the chemo treatments, Shapiro called the only person his age with cancer that he knew and asked him for the

best way to deal with the side effects. His friend answered him short and sweet: "Chemo's grim, man, get weed."

Hanging up the phone, Shapiro went into the living room and announced to his parents that he intended to purchase some marijuana to combat the pain from his treatment. There was an awkward silence. A debate followed between him and his mother, Ann, and ended with Shapiro being the loser.

An avid *Consumer Reports* shopper, Ann spent the next eight hours researching the world of marijuana. When she next saw her son, Ann appeared with a bong in one hand and a handful of money in the other with instructions to buy as much marijuana as he needed. Within minutes, Shapiro was on the phone and arranged to make a purchase. Upon his return from making the deal, his mother asked to see the goods. When Shapiro showed her the small bag, she inquired as to where the rest was.

"That's it, Ma," Shapiro said.

"Honey, give me the seeds," was her only reply.

By the end of the summer of 1987, 10 marijuana plants had grown to over 11 feet each in the Shapiro's back yard. "Far more weed than I could have smoked in a lifetime," he says.

## Preparation

When the chemotherapy ended, it was time to begin the radiation therapy treatments. There would be 15 treatments totaling 2,400 rads of radiation.

Shapiro had thoroughly researched the



A young Dan Shapiro with his mother Ann

subject and was well prepared for the meeting he requested with his radiation oncologist. With his father Mark in attendance, Shapiro riddled the oncologist with questions ranging from pulmonary difficulties to cardiac and spinal problems, and the side effects of the therapy: nausea, fatigue, sore throat and weight loss.

The barrage of questions was interrupted by the sobbing of his father, who tried to hide his tears by covering his face with his hands. Not wanting to draw attention to his dad, Shapiro continued on his line of questioning, now concentrating on other concerns: hair loss, skin burns, scheduling and parking.

Shapiro says the physician quickly put him at ease during the question and answer session. "He seemed forthcoming," Shapiro says. "When he wasn't sure, he said so. I felt I could trust him."

## Radiation Begins

"When we spoke about the radiation, my parents had been concerned," Shapiro says. "None of us had any experience with radiation or its side effects outside of PBS documentaries about Madame Curie, or Hiroshima and Nagasaki."

But compared to the recent chemother-

apy, Shapiro says that the radiation treatment was not that bad. "I had heard that I might burn a little from the radiation, like a sunburn, or have a parched throat, but compared to the side effects of chemotherapy, this would be a breeze. Two hundred and seventy rads down, only 2,100 to go," he says, referring to his first visit.

On the drive home that day, Shapiro decided to play a little prank on his family. A quick detour to the hardware store supplied him with a can of lime green paint. Arriving home, Shapiro sprayed the paint on his chest in a circular motion until the entire area was covered. After the paint dried he went into the living room where his mother was hanging a picture.

As rehearsed, Shapiro opened his shirt and in a quivering voice asked his mother, "Ma, what's happening to me?"

Ann looked over at her son and calmly said, "Lime suits your eyes. I hope you didn't get paint on anything in your bedroom."

Shapiro reassured her that he had been careful, then asked if it would be all right to try the gag on his father and brother. "No dear, you go right ahead and terrify the family," she said.

## Coping with Cancer

Before the diagnosis, Shapiro says that he had acquired a pile of paperbacks that he wanted to read such as titles from Stephen King, Erving Goffman and J.R.R. Tolkien. After his diagnosis, the book list drastically changed. Now he looked for titles that involved firsthand struggles. Books such as *Papillon* and *All Quiet on the Western Front* and topics, such as the life of Mohandas Gandhi and the Warsaw ghetto fighters, would now occupy his time.

"Though the books never revealed where the strength came from," he says, "in each story there was a handful of people who clawed a path toward thriving, even in the midst of overwhelming horrors. They clenched their fists, found a greater purpose, disciplined themselves and followed a realistic, determined hopefulness."

As he finished his last radiation treat-

ment, Shapiro thought that he would feel relieved. Instead, he was overcome with an uneasiness that left him tossing and turning all night long. "From now on, I'd have to live not knowing if the disease was going to come back."

In November 1987, Shapiro's chest CT revealed some residual mass, but physicians believed it to be scar tissue. Shapiro was told he was in complete remission and given a 70 percent chance of long-term, disease-free survival.

## First Relapse

The following year, Shapiro graduated from Vassar and entered the PhD program for clinical psychology at the University of Florida in Gainesville. The program meant he would be spending a lot of time at the university's affiliated medical facility, Shands Hospital. It was there he met his future wife Terry, who was the nursing director of the hospital's bone marrow transplant unit. Before long they began dating and soon moved in together.

As part of his graduate school studies, Shapiro worked with patients. His first assignment was a young teenage girl in the bone marrow transplant unit diagnosed with Hodgkin's disease. She hadn't spoken in over three weeks and her physicians were concerned that she had fallen into depression or had suffered neurological damage from the chemotherapy or radiation treatments.

Shapiro spent as much time as he could with the girl, whenever his classes allowed. He finally got the girl to talk and the two became friends. After 60 days in the bone marrow transplant unit, the teen was allowed to return home. Shapiro visited the girl two months later, only to find her body in a dilapidated state. Dan consoled her and left. She died the next day.

The girl's death made Shapiro reflect. "I knew that oncologists frequently offered aggressive treatments to patients even when the odds were grim," he says, "and I'd never seen a patient with Hodgkin's disease survive a transplant. I knew there were some who had, but I'd never met one."

Six months later, his relapse was diagnosed when a CT scan revealed a possible increase in the residual mediastinal mass. Shapiro was given chemotherapy followed by a bone marrow transplant. His physicians

gave him a 75 percent chance of surviving the transplant, but only a 40 percent chance of living more than five years.

Ironically, his room at Shands was the same room his first patient had occupied only eight months before.

The transplant left him bald, weak, swollen and mentally strained. Shapiro took to pencil and paper to record his experience and "liberate me for a few moments from my struggle."

"For some people, talking to a friend releases internal demons," he says. "For me, writing of my experience brushes a healing balm of perspective on them. I understand the 'why' and 'how' of things after I write them down. I understand what I want and what I don't want."

After 30 days in the bone marrow transplant unit and another 30 days recuperating at home, Shapiro was ready to return to his graduate studies. Seeing patients again, however, would take a little more time.

### Sharing the Experience

"It took a while, but eventually I was ready to see patients again. It was challenging. Years later, I would learn to tell patients that I, too, had been through a cancer experience, but months after the transplant, when I was just venturing back into those rooms as a young professional, I was still too raw," he says.

But later, Shapiro says he found his niche when he could see how patients would benefit from his experiences.

"I like what it did to me," Shapiro says of his ordeal. "I like that I remember how badly I longed for trivial worries. How I wanted to obsess about a flat tire, or a maligning, throat-tightening remark from a colleague, or a bill long overdue. It lets me play in trivialities without getting lost in them."

He adds: "I only wish that the memories could be evacuated from my dreams. I'm tired of the haunting explosions into wakefulness, bolt upright at 3 a.m., raising my arms to protect myself from unseen demons."

### Second Relapse

In 1991, Shapiro suffered a second relapse. In order to receive chemotherapy and radiation treatment from a highly recommended oncologist, he and Terry

moved to Stanford, Calif., for his last chance at a cure. Not knowing what the future held, Dan and Terry decided to take control over what they could. The couple married the day before they moved to the West Coast.

After checking Shapiro's medical history and going over his body from head to toe for tumors, the physician remarked: "I don't think I can cure you, but I'm going to try."

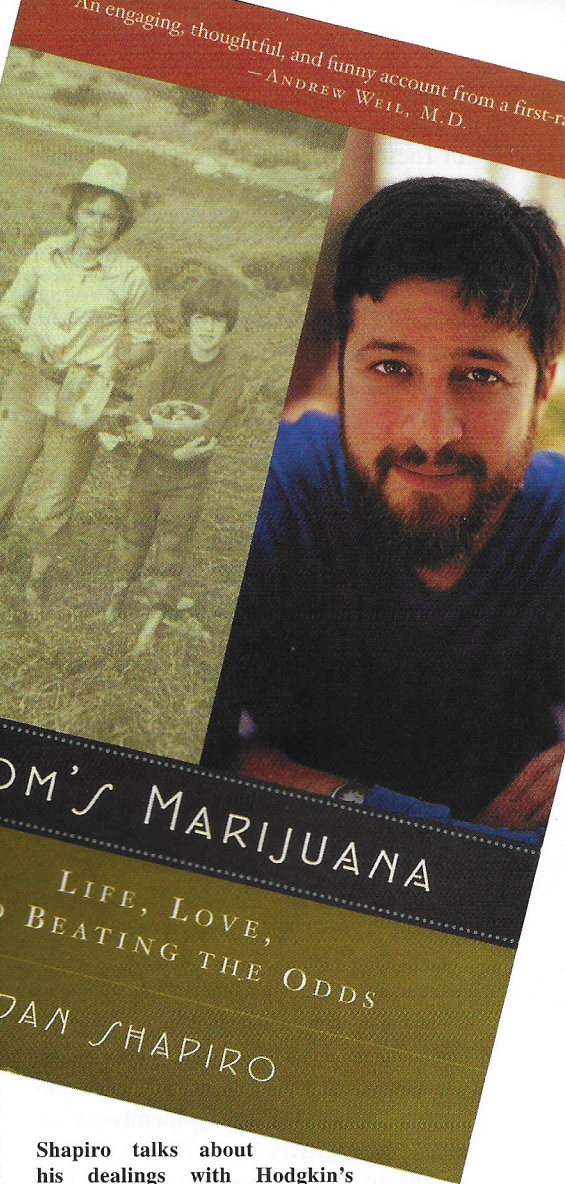
"Oncologists are drawn to the good fight, to the opportunity to fight a monster on the frontline," Shapiro says. "They are drawn to the magic of rescuing a life from the jaws of the enemy, but soon they find the faces of their patients haunting them. No one has taught them that they need to talk about their losses, that they must mourn the deaths of the patients they grew so fond of."

Shapiro says that bringing himself to the hospital at this stage was an act of faith. "I entrusted my body, my life's only vehicle, to strangers — strangers whose attitudes and ethics I could not assess. Lying on gurneys, in waiting rooms, in hospital beds and under scanners, I'd often worry. What if they didn't care enough and just screw this up. What if they're having a bad day?"

This time, the therapy was especially tough on Shapiro's body. Multiple infections attacked his body as well nausea and fatigue. "My body was deteriorating before me. I'd lost 40 pounds. I could no longer open doors or climb stairs without help. I moved more slowly, awkwardly. I slept more. Ate less."

After all this, he started saying his goodbyes. "For me, the dying process was about letting go memories and the emotions each evoked while my body slowly stopped," he adds.

The money the couple received from their wedding ran out quickly. Even with financial help from friends and family,



Shapiro talks about his dealings with Hodgkin's disease and the road to recovery in his book *Mom's Marijuana: Life, Love, and Beating the Odds* (Vintage Books).

within eight weeks of arriving in California, the couple was broke. Terry got a part-time job as a consultant that took her two hours away from home, as Shapiro battled the devastating effects of chemotherapy.

And just when things looked as if they couldn't get any darker, Shapiro's next set of X-rays revealed the biggest surprise of all: The tumor was completely gone. "Like a man emerging from years of solitary confinement who turns his face upward and squints towards the sun, I was basking in hope's reward for the first time," he says.

But even then, physician reports did not give him a good chance for long-term survival. That was in 1992.

An X-ray and CT scan in November 1999 showed no evidence of disease.

## Helping Others

These days, Dan Shapiro, PhD, lives in Tucson, Ariz., with his wife Terry and their two daughters, Alexandra and Abby. He is an assistant professor of clinical psychiatry at the University of Arizona in Tucson, where, he says, that his "fundamental role is to work with physicians, helping them unlearn years of denying their own needs, repressing their feelings about their patients and not taking care of themselves."

In 2000, he published *Mom's Marijuana: Life, Love, and Beating the Odds* (Vintage Books), a collection of his experiences dealing with his cancer. He is currently working on a second book, "Delivering Doctor Amelia" (Vintage Books), that deals with a physician coping with a costly mistake.

He also spends his time traveling the country giving talks to healthcare professionals. "With larger groups, I perform my essays and chat a bit," Shapiro says. "With smaller groups I create experiences to communicate that to be a good doctor one must appreciate one's own humanity."

In one of his group exercises, Shapiro blindfolds one of the participants and makes that person stand in the center of a circle formed by the other participants. The person is spun around, then sent walking until they reach another member of the group. They are then sent back across the middle to find another participant. This goes on a few times, until eventually the blindfold is removed.

Shapiro says that this exercise lets the physicians see their own vulnerability. "They are oblivious to what it feels like to wait, sleepless, in the darkest part of the morning, for surgery, a chemotherapy hit, a radiation treatment," he says. "A few simple steps in the dark in the hopes that the next time they see one of us coming, they pause and offer comfort, help us see what they see before sending us back across the dark circle alone."

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## Patient Education at Fox Chase

At Fox Chase Cancer Center in Philadelphia, social worker Susan Haney, LSW, helps cancer patients cope with both their diagnosis and their treatments.

"One of the prominent things that I have seen is the anxiety that people have regarding the actual radiation itself," Haney says. "From a professional standpoint, we really need to give a lot of education." She says that prior to radiation treatment, education programs and individual sessions are imperative to explain radiation safety to the patient.

"Here at Fox Chase, prior to treatment, every patient meets with both the radiation oncologist and the radiation oncologist nurse for consult," says staff nurse Cynthia Briola, RN, OCN. "During the initial consult, the nurse will review all potential side effects that the patient may receive." At that time, she says, the nurse may tell the patient what can be done if a certain side effect occurs.

Patient reassurance is essential. Haney says that wary patients need to be informed that they are only getting the radiation dose that they need. It is also important for the patient to have someone with them when the radiation therapy treatment is being discussed with the physician, she adds.

"Ofentimes, it can be overwhelming just to be diagnosed with cancer," Haney says. "But having someone else hear the same thing and then both being able to dissect that information afterward is very helpful."

"Our physicians are going to spend a tremendous amount of time with the patients explaining the entire procedure and welcome their questions and comments about the treatment so that we can make this the safest, most comfortable treatment experience that they have," she says.

Penny Anderson, MD, radiation oncologist at Fox Chase, says that she helps her patients through the therapy with "a lot of talking, hand holding, giving them time to talk and just work it through." Spending time with patients could provide them with support they might need, like social services or even talking to someone who has gone through the treatments, she adds.

"I could spend hours talking with patients, either in the clinic or on the phone — as much as they need," says Anderson. "They know that when they go for their treatments, we are always here for them everyday."

Another major concern is isolation, Haney says. Many cancer patients experience isolation from their friends and family because of the very nature of their disease. She has found that people tend to pull away from cancer patients rather than stay close to them.

Patient isolation can also come from the machine itself. "The radiation room can be a pretty sterile, cold environment," says Haney. "You're put on a table and then you are isolated. This experience in itself can be very traumatic to be left in that room, where you have time to think about your aloneness."

"It is important for people to know that they have control over some of the things that are happening in their treatment," Haney says. If things are going too fast for them or they have questions while we are doing something, they need to know that we'll be there and explain it step-by-step as we go through the process of bringing them through a full treatment."

— T. S.

