

ASCO Expert Corner: Giving Patients a Way to Share Their Stories



Listen to the *Cancer.Net* Podcast: *Seize the Days, with Evan Lipson, MD* [1].



ASCO member Evan J. Lipson, MD, launched a website that offers people with cancer and their families an opportunity to record

and preserve audio interviews as a way to share their personal stories with others. Here, Cancer.Net talks with Dr. Lipson to learn more about why he created this website, SeizetheDays.org [2].

Q: Can you give a brief description of your website, including what people can expect when they visit?

A: Seize the Days is a project that celebrates people living with cancer and explores the ways they make their days meaningful. It gives patients and their loved ones an opportunity to record and share their stories using broadcast-quality audio interviews that are presented online at SeizetheDays.org [3].

For example, one woman with advanced breast cancer talks about how she started a foundation to benefit other patients who share her diagnosis—an experience she calls the most rewarding of her life. Another interview describes a woman who made quilts for her two daughters as a way to leave behind her warmth and love. The site features these and other stories that describe the interesting and meaningful ways that cancer patients add life to their days.

Q: What motivated you to create this website?

A: Shortly after I became an oncologist, I learned about a woman named Cyndi who had pancreatic cancer. She was a nutritionist by profession and had spent much of her life collecting recipes from around the world. After she was diagnosed, Cyndi began to think about ways to share her knowledge and passion with the world. She started by giving a cooking lesson to two women she knew and ended up, with the encouragement of some friends, writing a cookbook.

Cyndi knew exactly how she wanted the cookbook to look. Even in her last weeks of life, when she slept most of the day and spoke little if at all, Cyndi would indicate a preference when it came time to make a decision about the cookbook. She made it clear that she wanted the book shared far and wide, without regard to copyrights or royalties. She found tremendous satisfaction in knowing that her work, her creation, would live on.

In a way, it seemed that the book and Cyndi kept each other alive. Had she not gotten sick, the book might never have been written. And, as her friends will attest, creating the book gave Cyndi a unique reason to fight her disease each day. She lived more than a year longer than her doctors had predicted.

I was moved by Cyndi's dedication and fascinated by how her sense of purpose brought her such satisfaction. I began talking with my patients about the positive changes that had been brought about in the wake of their diagnoses. As it turned out, they had lots to say. A website seemed like an ideal place to showcase and preserve those stories.

Q: What type of response has the site received?

A: Seize the Days has been extraordinarily well received. Thousands of people from across the globe have visited the site. In addition, patients and their family members have been generous with their time and enthusiastic about sharing their stories. For some participants, speaking openly about a loved one has been a source of healing. One family from South America heard my brief, edited interview with their relative and requested a copy of our entire 45-minute conversation as a way to remember him. My colleagues have also been very supportive and continue to introduce me to their patients who have stories to tell.

Q: What are some of the themes that have emerged from your interviews with patients? What have you learned?

A: It turns out that people living with cancer add life to their days in all sorts of interesting and remarkable ways. Some people strengthen relationships with loved ones, becoming even closer with family and friends. One man with lung cancer I spoke with is back in touch with his children

after having been estranged for many years. Other people concentrate on activism, starting foundations or fundraising. Some derive fulfillment by creating somethingâ€”art, poetry, or music. These creations help patients express emotions, leave a legacy, or regain a sense of control. Creations come in all shapes and sizes; one of my patients recently began taking steel drum lessons!

Q: Based on some of the concepts that have been explored on SeizetheDays.org, you wrote an essay that is being published this month in ASCO's *Journal of Clinical Oncology* (JCO, April 1, 2011 vol. 29 no. 10, 1392-1393)[4]. It is part of the JCO ?Art of Oncology[5] ? series in which doctors write about the emotional challenges experienced in providing cancer care. What does Seize the Days contribute to the Art of Oncology series, and why is it important for the cancer community?

A: Much of what we do as oncologists is about helping our patients live full, meaningful lives for as long as possible. In an effort to ?treat the whole person,? we focus not only on treatment options in an effort to extend life but also on helping patients find contentment and tranquility in their day-to-day lives. It can be challenging to know how to advise patients in that regard. I hope that Seize the Days not only inspires and informs patients but that it helps doctors, nurses and other care providers guide patients toward rewarding, fulfilling ways to add life to their days.

Dr. Lipson is Chief Fellow in Medical Oncology at the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins in Baltimore, Maryland.

Links:

[1] http://www.cancer.net/sites/cancer.net/files/Seize_the_Days.mp3

[2] <http://SeizetheDays.org>

[3] <http://seizethedays.org/>

[4] <http://jco.ascopubs.org/content/29/10/1392.full>

[5] <http://www.cancer.net/patient/Publications+and+Resources/The+Oncologist%27s+Perspective>