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MyLifeLine.org Cancer Foundation: Free, Personalized Websites for People with Cancer

Editor's Note: This is part of a series of Patient Advocate Guest Columns and Podcasts, launched as a forum for patient advocates to address a topic, issue, or trend within the cancer community through Cancer.Net, the patient information website of the American Society of Clinical Oncology (ASCO).

MyLifeLine.org Cancer Foundation: Free, Personalized Websites for People with Cancer

A patient advocate guest column by: Marcia Donziger, Founder and Executive Director

At the age of 27, I was diagnosed with stage IIIc ovarian cancer. During the treatment process (surgery followed by six months of chemotherapy), I struggled with how to communicate effectively with friends and family. I couldn't call people back in time when I was sick, and it was depressing to repeat the same information over and over.

In 2003, my friend Lori was diagnosed with brain cancer at age 33. Lori's friends owned a web company and created a beautiful website for her family to easily communicate with loved ones during the treatment process. I knew immediately that this was a tool that would have been incredibly helpful during my own recovery. Unfortunately, Lori passed away at age 35. After she died, I kept thinking about the incredible support Lori received during her last two years of life. Lori's mom called the website their family's ?lifeline.? Thus, MyLifeLine.org Cancer Foundation was born in 2007 in Lori's memory.

At MyLifeLine.org Cancer Foundation, we believe that a strong support community is critical for people with cancer. Research proves that when a patient has a strong support community, treatment compliance and healing outcomes improve. Every day we provide free, personal websites to cancer patients and caregivers so that they can easily connect with family and friends, because no patient should ever feel alone. Since 2007, MyLifeLine.org has steadily grown to support over 30,000 people, including patients, caregivers, friends, and family.

Today, people tell us they are overwhelmed with email messages, phone calls, and text messages. MyLifeLine.org is the only personal website service that consolidates all caregiving needs in one place and focuses 100 percent on tools people can use to make their lives easier during their cancer treatment.

?MyLifeLine was the best thing to help me recover. I never felt alone. Thank you for such a great service.? -MyLifeLine.org Member

We know that patients are often stuck in waiting rooms and infusion areas for hours with only a phone to reach out to everyone at once. Our next innovation is a mobile version and iPhone application, adding the convenience of accessing personal websites from anywhere at any time.

Patients choose the privacy level and design of their personal site. Choices are available during the set-up process and can be changed at any time. Features of personal websites on MyLifeLine.org include:

The **Helping Calendar** is the place to add chemotherapy & radiation therapy schedules. Here patients can ask for help like a friend to accompany them to these appointments, so they won't feel alone. This can alleviate many duties from the main caregiver.

The **Laughing Medicine** is where a new joke is posted every 24 hours to give people a reason to smile everyday.

The **Giving Angels** page is where patients can set up a personal fundraiser to raise money needed for medical costs not covered by insurance.

My Updates is the place to share health updates. This relieves the burden of repeating updates multiple times.

The **Guest Messages** page is where friends and family can post a message and inspire patients through notes of love and encouragement.

The **Learning Links** page enables the patient to share information on the specific cancer they have, so they don't have to explain the medical details multiple times, and friends and family don't feel awkward asking questions of the patient.

Collaborating with cancer centers and nonprofit organizations is our number one initiative for finding more patients and families who can benefit from MyLifeLine.org. Strategic partners expand our ability to reach more people and improve patient outcomes, because a strong support community is critical to healing and recovery.

To demonstrate the impact of MyLifeLine.org, I would like to share the story of Don and Rebekah. Rebekah struggled with pancreatic cancer beginning in February 2009. At first, she was against having a website to communicate with loved ones. But Don pressed her to let him create it. Once they started, the support was overwhelming. Over 100 friends waited anxiously for updates on Rebekah. Because of the Helping Calendar, people signed up to drive for each of Rebekah's chemotherapy and radiation therapy appointments. Rebekah and Don also had a steady stream of meals during that time. And MyLifeLine.org allowed Don to continue working, without having to take vacation leave.

?This could not have happened without your website. It has made our lives easier in spite of the tremendous stress we are under.? - Don

To view a sample patient site, please go to our homepage and click on the Take a Tour button. From our homepage, any patient or caregiver can set up a free, personal website, at www.mylifeline.org [1].

If you are a patient advocate interested in authoring a future Patient Advocate Guest Column or Podcast, please contact patientadvocates@asco.org [2] or 571-483-1358.

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Links:
[1] http://www.mylifeline.org
[2] mailto:patientadvocates@asco.org