



# Unique but not Alone

*Advances in psychosocial resources help young adult cancer patients find support and excellent care.*

By Bridget McCrea

MELISSA WALLER COULDN'T believe her ears. After experiencing pain in various parts of her body for months, she was diagnosed with stage IV lung cancer (adenocarcinoma) at the age of 31. The news came after roughly five months of medical testing, the result of recurring back and tailbone pain and bouts of pneumonia that started in 2008.

Not so long ago, young patients like Melissa met an additional challenge when facing a cancer diagnosis: a lack of resources geared toward the issues specific to young adults (a group, according to a 2006 report by the Adolescent and Young Adult Oncology Progress Review Group, that includes patients between the ages of 15 and 40). Melissa's ability to cope with the disease would have been limited by the few resources available to her as a young adult and by the size of her own personal support team. Now, thanks to advances in the number of psychosocial networks, Web sites, and support groups developed for young adult patients, Melissa has a much deeper pool of support to draw from as she adjusts to the new reality of moving forward as a young woman living with cancer.

And moving forward is just what Melissa hopes to do. A resident of Phoenix, Arizona, she continues to enjoy life despite the physical impact and the side effects of treatment. She has a large circle of friends and remains employed as an interactive development sales manager for a large firm (although she is currently on long-term disability) that provides her with comprehensive health care coverage.

Although her colleagues and friends have been extremely supportive, Melissa acknowledges the difficulties of her new normal. "I miss my colleagues and even the challenges and stresses of the work environment," she says. Being diagnosed with



Melissa Waller

cancer, she adds, has “completely turned [her] life inside out,” particularly when it comes to planning for the future—a privilege many of us take for granted.

Early on, uncertainty about the future was the focus of much of her worry, as Melissa was forced to make decisions about fertility. “The issue of fertility was one of my first concerns,” she says. Confronted with the decision of whether to freeze an embryo for future fertilization before she began chemotherapy treatments, Melissa found herself facing decisions she had never dreamed of having to make. “I was on the phone, talking to people all over the country about fertility and trying to figure out what to do,” she says. (After factoring in the expense and the steps involved with freezing an embryo, Melissa decided against it.)

Another key consideration for Melissa was her two-and-a-half-year-long relationship with her boyfriend, who was sitting with her in the examination room

when she was diagnosed with lung cancer. It was then that the pair learned there was no cure for the disease and that the average prognosis ranged from one and a half to two years. Anticipating the strain that cancer could put on the relationship, Melissa gave her boyfriend the option to move on with his life and with no hard feelings.

“I gave him an ‘out’ option right away,” Melissa says. Particularly concerned about her inability to plan for the future, including marriage, children, family, and career, she wanted to be clear at the outset. “I told him that I’d love it if he came along with me on this journey, but I didn’t expect him to be there by my side. That’s a lot to ask from someone.”

Melissa also grapples with uncertainty about how her work life will ultimately unfold. Ideally, she says, she’d like to have the option to work either on a part-time basis or to perform some work from home. “At this point in time, they don’t

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want me doing that,” Melissa says. “I will probably either need to go back to work 100 percent, stay on long-term disability, or find another job.”

#### For Young Adults, Positive Changes

The issues that Melissa is coping with as a result of her diagnosis—including those related to fertility, relationships, and career—are common among the young adult cancer community. To these young people, Brandon Hayes-Lattin, MD, director of the Adolescent and Young Adult Oncology Program at Oregon Health & Science University in Portland, says, “You’re not alone.” Even patients who lack sizable personal networks of friends, family, and supporters can tap into a myriad of resources designed to assist with the psychosocial side effects of cancer.

“There have been major advances in creating a discipline around adolescent and young adult oncology in the past

three years,” says Dr. Hayes-Lattin, who adds that young adults with cancer often deal with isolation, knowing they’re the “only ones” in their social group who have the disease. “They don’t know anyone else their age who is dealing with it, so they go into isolation.”

Social networking, which Melissa uses regularly through her own online blog (*themelissawaller.com*) and sites like Facebook, has helped ease that isolation for many young patients. “These online tools are helping to connect patients to one another,” says Dr. Hayes-Lattin, who points to groups like Imerman Angels, which links cancer patients with survivors of their specific disease, as an even more direct route for young adults looking to connect.

Planet Cancer, which has a social networking platform called My Planet, is another way to break the isolation blues, allowing participants to create an identity and join a group. “This provides a virtual way to share your story with others,” says Dr. Hayes-Lattin, “and also gain access to care, which is a particularly important point, considering the high numbers of young adults who are either uninsured or underinsured.”

Spurred on by the 2006 collaboration between the National Cancer Institute and the Lance Armstrong Foundation that resulted in the comprehensive report *Closing the Gap: Research and Care Imperatives for Adolescent and Young Adults with Cancer*, the movement to increase resources for young adult cancer patients has been progressing steadily. Part of that movement includes a commitment on the part of providers to deliver excellent service across the cancer continuum—from

## RESOURCES FOR YOUNG ADULTS

### LiveSTRONG Young Adult Alliance [livestrong.org](http://livestrong.org)

The LiveSTRONG Young Adult Alliance is a coalition of organizations with the goal of improving the survival rates and the quality of life for young adults with cancer between the ages of 15 and 40. The alliance is committed to promoting research and the investigation of the problem, serving as a voice for the issue and promoting effective solutions.

### Imerman Angels [imermanangels.org](http://imermanangels.org)

Imerman Angels connects a person fighting cancer today (“cancer fighter”) with someone who has beaten the same type of cancer (“cancer survivor”). The relationship provides a fighter with the opportunity to ask personal questions and receive encouragement from someone who is uniquely familiar with the situation. The relationship provides a survivor with the opportunity to personally help a fighter as he or she battles the disease.

### American Cancer Society [cancer.org](http://cancer.org)

The American Cancer Society (ACS) is a nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service.

### Fertile Hope [fertilehope.com](http://fertilehope.com)

Fertile Hope is a national, nonprofit organization dedicated to providing reproductive information, support, and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

### Young Survival Coalition [youngsurvival.org](http://youngsurvival.org)

Young Survival Coalition (YSC) is the premier international organization dedicated to the critical issues unique to young women and breast cancer. YSC works with survivors, caregivers, and the medical, research, advocacy, and legislative communities to increase the quality and the quantity of life for women ages 40 and under diagnosed with breast cancer.

### Planet Cancer [planetcancer.org](http://planetcancer.org)

An online community comprising young adults with cancer, the organization provides networking opportunities, hosts retreats, and educates young survivors.

### I’m Too Young for This! [i2y.com](http://i2y.com)

Founded by young adult survivors for young adult survivors, the I’m Too Young for This! Cancer Foundation is a global leader in the fight against cancer, working exclusively on behalf of survivors and their care providers under the age of 40.

diagnosis through survivorship.

“The goal is to make sure young adult patients have a place to be that isn’t the pediatric facility and that also isn’t a place where everyone looks like their grandparents,” explains Dr. Hayes-Lattin. He points to the LiveSTRONG Young Adult Alliance and its 100-plus member organizations as a particularly strong force in helping create that sense of place for young adults. From the organization’s resource page (see sidebar on previous page), young adults can access information about physical, emotional, relationship, and practical issues as well as community resources.

#### The Future Is Bright

With technology continuing to change the way the world communicates and interacts, the Internet will no doubt offer increasingly varied and more specific support resources for young adults. This growing body of resources, combined with increasing commitment on the part of health care providers to acknowledge the unique issues facing young adult cancer patients, bodes well for the lives of young patients.

For Melissa, maintaining perspective on her diagnosis and all that lies ahead has been crucial. She advises young patients to tackle the disease day by day and piece by piece rather than let the “big picture” become too overwhelming. “Enjoy life and all that you’ve been given,” she says, “and always maintain a positive attitude.” **CFThrive**

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