

When
CANCER
STRIKES
a Friend

What to Say, What to Do, and How to Help

- Finding your way as a friend
 - Gifts of friendship
 - Understanding the cancer experience
 - Sharing hope, peace, and spiritual care
 - Learning to communicate
 - And more!
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Bonnie E. Draeger

Parents of pediatric patients need friends who are available for last minute requests—friends who don't mind hearing, "Matt hasn't been eating and suddenly today he's hungry for _____. Could you run over to get some and bring it to the hospital?"

Friends who *directly* help out the patient's family, *indirectly* give ill children more time to spend with their parents. Enabling parents to stay in close proximity to hospitalized children is a gift to both of them. You can research local Ronald McDonald houses or area churches/mosques/synagogues that may be willing to assist parents living away from home. You can also ask the cancer care center if they have a list of nearby accommodations or if they provide social workers to help families. Remember, cancer or no cancer, pediatric patients are first and foremost kids. They may not feel up to regular activities on some days, but on others they work through the pain to enjoy things children love—fishing off the hospital pier, pigging out on hot dogs or powdered sugar doughnuts, or just playing with their favorite toys.

Modern technology also enables hospitalized or homebound students to Skype with friends and classmates. Many young patients have access to iPads or laptops; if not, schools or friends can pool resources to provide them for the patient and his/her family. Young patients and their families may also request that someone act as a liaison with the school, e.g., pick up/deliver school assignments or keep in touch with teachers.

Finally, spend time with pediatric patients—reading or playing computer games, cards, and board games. (Check with the pediatric cancer center to see if healthy children can visit.) And remember when you send gifts to pediatric cancer patients, it is in the child's best interest to space out gifts and not to overdo. Instead, try sending a package of smaller gifts for parents to distribute at appropriate times, rather than one over-the-top gift.

No matter what you choose to do, or how you choose to help, always remember that cancer impacts an entire family, not just the pediatric patient. The whole family benefits when friends nurture *each and every family member*.

TEENS AND YOUNG ADULTS

At least two hundred and seventy thousand of today's cancer survivors were diagnosed before the age of twenty-one.⁶ Amy Blumenfeld⁷ is the voice of young-adult cancer survivorship. She is an accomplished journalist and childhood-cancer survivor who gives us a personal and candid perspective on the unique cancer challenges faced by teens and young adults. She also discusses how you can help them.

Cancer as a Teen or Young Adult

by Amy Blumenfeld, MS

Friendship is particularly precious for teens and young adults battling disease during the formative years of their lives. Pre-teen years and adolescence are challenging years for everyone. It's an awkward time when our bodies grow and rebel with pimples, growth spurts, and vocal chord changes. When that same body wages a war against itself even further by developing cancer in the midst of puberty, it's asking a lot physically. To lose your hair from chemo when you're ready for your first kiss—and to know you need Mom and Dad's assistance with the most personal of tasks while simultaneously attempting to establish your independence—is asking a lot emotionally. To conquer the disease and emerge from it all as a healthy, productive person, and fade into society with few physical scars, is simply a miracle.

Unlike adult patients who have lived several decades as healthy, productive individuals, these kids are in the midst of growing up when first diagnosed and treated.

The Issues

Everyone with cancer has concerns no matter what their age—the possibility of relapse, fear of the unknown, and acceptance

⁶ National Cancer Institute, "The Childhood Cancer Survivor Study: An Overview," originally posted 01/10/2007, updated 06/06/2012. www.cancer.gov/cancertopics/coping/ccss.

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by peers both socially and professionally. Teen and young adult patients also have unique concerns.

People like me don't wonder in our 50's if our husbands will find us attractive post-mastectomy or if we will have the stamina to run around with our grandchildren after a dose of chemo. Instead, we pray as eighth graders that the drugs and radiation we have received will not only spare our lives, but our fertility as well—even at an age when the concept of having our own children is virtually impossible to grasp.

Later on, we fear rejection from a potential spouse once we disclose not only our history of illness, but also the possibility that we may never be able to conceive. Will we be branded as damaged goods? And if that is a potential reaction, should we disclose our illness at the start of a relationship, or wait, only to risk losing someone we have grown to love?

Furthermore, how will cancer impact our careers? Adult patients and survivors have had years to establish themselves professionally. As teens and young adults, we are just starting out. If our first employer is informed of our recent battle, will we be rejected because of a concern we may relapse on the job, or will our status as a "fighter" and "survivor" work to our advantage?

The issues facing those of us who struggle with cancer before adulthood are many. Here is a sampling of our concerns, the issues we face, and how you can help:

Hair Loss

Hair loss is traumatic at any age, but can be particularly challenging during adolescence—a time fraught with insecurity. In fact, it's not unusual for some children and teens to have a greater fear of hair loss than death. In the minds of teens, kids are immortal; but hair loss is social death, particularly for girls. It is emotionally debilitating, alienating, and some are convinced that their appearance will scare away friends, not to mention potential partners. Others, however, find hair loss to be empowering. The crumbling of facades and being forced to confront the world as a pasty, follicularly-challenged teen can uncover a latent inner strength and the existence of an unknown steel.

As a friend, the most important message you can convey is: "I love you for what is on the inside, not the outside." How you express and drive home that message is up to you. Shave your head in solidarity? Shower her with funky scarves and him with baseball caps? Grow out your own hair to donate to an organization like Locks of Love that makes wigs for kids with cancer?⁸ Go to a salon for makeovers and a day of beauty? Whatever you do, make it fun and be sure she knows you are by her side no matter how she looks.

New Family Dynamics

Another rite of passage often experienced by survivors of childhood and adolescent disease is changing relationships with parents and siblings. During illness, parents were the caretakers, and many needs of healthy siblings may have been temporarily placed on the back burner. Now that the patient (adolescent) is healthy, there is a new dynamic. Transitioning from a family in a cancer crisis to a family post-crisis is certainly welcome, but it comes with its share of growing pains.

For instance, during illness, there was likely a lack of physical privacy for patients—they were dependent on parents for even the most personal of tasks. Now, there are new boundaries that parents must respect. Healthy siblings may feel resentful. The patient may feel guilty for having "stolen" parents' attention. When treatment ends, every family shifts gears regardless of the issues. As a friend, you may be just the right person to hold the survivor's hand as she jumps these emotional and personal hurdles.

Disclosure and Relationships

How do you tell someone you have just started dating that you recently overcame a life-threatening illness, that it could relapse, that the treatment put you at higher risk for a secondary cancer, and that it might have left you infertile? The answer: Gracefully.

⁸ Locks of Love is a public not-for-profit that creates hairpieces for children in need under twenty-one, who suffer long-term or permanent medical hair loss due to cancer and other medical conditions. Hairpieces are fashioned from donated hair (www.locksoflove.org).

There is no easy way for a young cancer survivor to disclose the long-term effects of his cancer treatment with a potential spouse. He'll hope for the best, but expect the worst. Survivors' minds are flooded with questions: Should I start the conversation early in the relationship to spare rejection later on when I have fallen in love? Or will doing so cause the other person to feel I am propelling the relationship forward at warp speed?

If you are a friend who is dating a young cancer survivor, don't feel guilty if you have reservations about entering into a serious relationship. Think everything through. Be honest with yourself and with your partner. Once you commit to being with a survivor long-term, you inherit all of their medical and emotional concerns, making you, in a sense, a side effect of their side effects. If the survivor has a weak immune system, it may impact everything from travel plans to everyday life. If the survivor is infertile or needs medical assistance in creating a family, there are physical, emotional, and financial matters that you should be aware of. If you marry the survivor, what happens if they don't qualify for life insurance because of their medical history?

Life is an unknown, especially in the world of cancer. As the significant other, ask yourself, "Am I emotionally prepared should cancer reappear? If need be, am I comfortable being a caretaker?" Most people will rise to the occasion, but if you find yourself becoming anxious just thinking about the possibility, you might want to speak with a medical professional. Having an expert answer some of your questions may help quell some of your fears. Also, there are plenty of support groups for partners—check with your local hospital or any national cancer organization for their local chapters.

Every year seventy-two thousand adolescents and young adults are diagnosed with cancer.⁹ While their futures hold unanswered questions, their tenacity, courage, and resolve deserve our highest respect and serve as examples to all of us.

⁹ Fifteen to thirty-nine years of age. Statistics from: "Adolescents and Young Adults with Cancer," National Cancer Institute. (www.cancer.gov, accessed 11/2/2011).

New Beginnings

by Amy Blumenfeld, MS

It wasn't until I started dating seriously that disclosure became an issue. In no way was I ashamed of my cancer history; in fact, there was an element of pride in having overcome a life-threatening disease at a young age. But I knew that even the greatest guy in the world would have reason to pause before marrying someone who could relapse, develop a secondary cancer, or be infertile.

By all accounts, my health and fertility were intact, but given that my treatment was intense and experimental, not even the most-renowned doctors could accurately predict the future.

In 2000, at the age of twenty-six, I found that great guy. His response was better than I had ever expected. He was interested in all aspects of my history; he was proud of what I had overcome, and when I told him I didn't know if we would be able to have a child, his response was, without skipping a beat, "So, we'll adopt." When we wed two years later, Dan knew he was marrying me as well as my survivorship—for better or worse.

A couple of years later, we learned that the high-dose radiation had damaged my uterus so severely that I am incapable of carrying a pregnancy to term. However, because my doctors had the foresight when I was fourteen years old to shift my ovaries out of the line of radiation and shield them, my eggs remained healthy and I was able to have my own biological child. With the help of in vitro fertilization, we created our own genetic embryo and transferred it to another woman's uterus. She became pregnant with our baby and, to our great joy delivered our daughter in February 2006.

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Freedom

by Amy Blumenfeld, MS

I recall the day I was discharged from Memorial Sloan-Kettering, after nearly two months in a reverse isolation room for an autologous bone marrow transplant. I was escorted through the hospital doors and onto Manhattan's York Avenue, where I sat in a wheelchair awaiting my ride home. I inhaled the sweet summer air as deeply as I could. Even the thick black exhaust from the trucks merging onto the Queensboro Bridge smelled divine. It's amazing what regaining your freedom can do to your senses.

Yet, as I sat there, acutely aware of every possible germ source, I felt more restricted than ever before. It was as if anything contagious had been highlighted. I envisioned dancing amoebae on taxi door handles. I squirmed when a child walking by coughed without covering his mouth. And upon hearing a sneeze, my eyes instantly darted to pinpoint its exact location.

Before discharge, doctors explained that the chemo and radiation had weakened my immunity to the point that I was highly susceptible to nearly any bug out there. Certain places, such as enclosed spaces without much fresh air, were off limits. No movie theaters. No restaurants. No public transportation. No mall. And it's a good thing I didn't like sushi because uncooked food was a thing of the past, at least for the time being. It was as if I was handed an instruction manual for freedom.

Fortunately, my friends and family were incredibly supportive. No pity. No coddling. Humor infused everything possible. They aimed to make recovery fun—a group project. We played highly competitive games of Scrabble in my parents' den. Our next-door neighbors cooked delicious authentic Italian meals they swore would boost my immune system. My cousins sent a garbage bag full of Max Factor

make-up so I could be the hottest bald fifteen-year-old girl in town. We baked cookies, rented movies, and our neighborhood walks lengthened as the weeks passed.

"It takes a village to raise a child," and I believe it can easily translate to healing a patient. My doctors drew up the battle plan and created the strategy, but my family and friends helped me fight and win.

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CANCER IN OLDER ADULTS

The likelihood of developing cancer increases with age. Nearly 30 percent of all cancers are diagnosed in people seventy-five years or older.¹⁰ This is a unique group of patients who are dealing with multiple health issues beyond cancer. In seeking expertise on cancer in older adults, I turned to Rev. Gloria Steadman-Sannermark, a registered nurse and clergywoman. Rev. Sannermark has been a hospice chaplain and currently ministers to older adults in the Sun Cities of Arizona.

When the Patient is Older

by Rev. Gloria Steadman-Sannermark, RN, MDiv

Two characteristics stand out when I observe older adults with cancer—attitude and overload. A fellow clergyman, Rev. Tim Smith, puts it this way, "Older adults have been through life's trials and tend to take the news [of cancer] with a *go-ahead-and-tell-me-attitude*. . . . They don't want to suffer, but they are not afraid to die."¹¹

¹⁰ SEER Cancer Statistics Review, 1975-2009 (Vintage 2009 Populations), "Table 1.10. Age Distribution (%) of Incidence Cases by Site, 2005-2009," National Cancer Institute, http://seer.cancer.gov/cst/1975_2009_pops09/.

¹¹ Rev. Tim Smith in an interview with Gloria Steadman-Sannermark (Phoenix, Arizona, 2006).