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In Cancer Fight, Teenagers Don't Fit In



Joshua Lott for The New York Times

NEEDS Serena Bellinger, 15, who in 2002 was told she had a brain tumor, found support among peers at the Wellness Community in Phoenix.

By **RONI CARYN RABIN**
Published: March 15, 2010

Simone Weinstein's ordeal with [cancer](#) started in the most banal way: she was tired. She had a hard time getting up in the morning, and did not even have the energy to hang out with her friends.

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Joshua Lott for The New York Times

OUTLET Heather Bongiolatti, 22, was told she had cancer at 14. She tried groups for adults and children, but neither quite fit.

But Simone was 14. Her mother thought she was just a typical teenager.

"She'd say, 'I don't know what to do with you,'" said Miss Weinstein, now a 20-year-old student at Whittier College in California, who was finally given a diagnosis of the blood cancer called acute lymphoblastic leukemia. "She thought I was being a normal, somewhat lazy, silly teenager."

That is not unusual, even though 1 in 333 children develops a malignancy by age 20, and the disease leads to more deaths in the 15-to-19 age group than any other single illness.

Experts say that since teenagers tend not to ask adults for help or confide about

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embarrassing physical changes, they are likely to receive their diagnoses much later in the course of their illness than younger children. And that usually means they will require more aggressive and protracted treatments that can lead to lifelong side effects.

While overall survival rates are as high as 70 to 80 percent, depending on the type of cancer, teenagers have not benefited from the huge advances in survival made by younger children and much older adults in recent decades. They are also far less likely to participate in clinical trials, which offer the most up-to-date therapies: Fewer than one in five adolescents with cancer are treated in a clinical trial, according to some estimates, compared with well over half of younger children.

Some basic questions about cancer in teenagers remain unresolved, including where it should be treated — in pediatric medical centers, along with toddlers, or in adult settings that follow protocols tested on significantly older patients?

And teenagers tend to develop a very different set of cancers from older adults. The most common are leukemias, lymphoma, cancers of the reproductive tract, [brain tumors](#) and sarcomas — cancers of the muscle and connective tissue that are often misidentified as sports injuries.

“Teenagers fall into a cancer gap — a real no-man’s land,” said Dr. W. Archie Bleyer of the St. Charles Medical Center in Bend, Ore., an expert on cancer in teenagers who was the keynote speaker at a conference on the subject last month in Phoenix at the Wellness Community-Arizona, an affiliate of the international group Cancer Support Community. “The 14-, 15- or 16-year-olds need psychosocial support, which they’re not going to get if they’re in an adult hospital.”

Teenagers treated at pediatric medical centers are far more likely to be enrolled in a clinical trial, Dr. Bleyer said, but he added, “Depending on the cancer, some are better off being treated at the adult center.”

The Arizona group started offering year-round social support to teenagers several years ago, after being approached by Heather Bongiolatti, a local high school student with non-[Hodgkin’s lymphoma](#).

She had tried support groups both for adults and for children, but neither quite fit the bill, she said in an interview, adding: “Most of the adults were parents of children with cancer. And the groups for kids were doing drawing and making crafts. I was 15, I didn’t want to do that.”

But she desperately needed a social outlet. Though two close friends stuck with her through her illness, most of her peers “dropped me off the side of the earth,” she said, acting as if they did not even know her when she returned to school after missing most of 9th and 10th grades.

Now 22, Miss Bongiolatti says most of her peers are graduating from college and getting on with their lives, while she has had to put hers on hold because of serious bone problems resulting from her cancer medications. She is unable to drive and has had nine operations in the past few years, including three hip replacements.

Gina DeGraw, a clinical social worker who runs a cancer survivors’ clinic for teenagers at Phoenix Children’s Hospital, said that while there is no good time in life to get cancer, the adolescent years may be among the hardest.

“The typical teen is seeking independence, and all of a sudden gets this diagnosis and guess what: they have to be dependent again,” she said. “They have all the angst of teenagers, and they have to deal with issues most adults don’t have to deal with, like contemplating the loss of their fertility.”

Not to mention their appearance. “Just when they want to look most attractive, they’re



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getting bloated and losing their hair” from radiation, [chemotherapy](#) and [steroids](#). Mrs. DeGraw said.

Teenagers can also lose [health insurance](#) when they age out of family or government plans at 18 or 19, or if they have to withdraw from college for medical reasons.

They may not be the best patients, either, doctors say, and may have a hard time sticking to long and grueling courses of treatment. Many of these concerns were [identified in a report](#) issued jointly in 2006 by the [National Cancer Institute](#) and the [Lance Armstrong Foundation](#). That report, which grouped adolescents with adults in their 20s and 30s, noted that this entire population “has seen little or no improvement in cancer survival rates in decades.”

That report led to the development of treatment programs focusing on the specific needs of adolescents and young adults. For example, the Knight Cancer Institute in Oregon has a multidisciplinary program that consults with pediatric and adult oncologists about available clinical trials and includes support services for its young patients, said Dr. Brandon Hayes-Lattin, medical director of the institute’s adolescent and young adult oncology program.

Clinical trials for this age group have led to some breakthroughs — especially when it comes to acute lymphoblastic leukemia, the form of cancer Simone Weinstein had, said Dr. Crystal L. Mackall, chief of the pediatric oncology branch of the National Cancer Institute.

Teenagers with this type of leukemia, often called A.L.L., do not fare as well as younger children with what appears to be the exact same disease, a discrepancy that has baffled oncologists. But when researchers compared teenagers treated by pediatric oncologists with those treated by adult cancer doctors, [they found](#) that the first group did remarkably better.

“When we saw the differences, I was floored,” said Dr. Wendy Stock, director of the leukemia program at the [University of Chicago](#) Medical Center. “It wasn’t a subtle 5-percentage-point difference, but a 30-percentage-point difference in survival.”

Now the pediatric protocol is being offered to teenagers through clinical trial sites. Dr. Stock and others are trying to figure out what factors are responsible for the better outcomes, and whether the greater survival is because of the treatment protocol itself or other factors, like the more structured environment of a pediatric center or pediatric oncologists’ greater familiarity with A.L.L.

There may even be subtle differences between the type of teenager or young adult who is referred to a pediatric center and the one who goes to an adult oncologist. Many of the drugs for this type of leukemia are oral ones taken at home, and require strict adherence for an extended period. “The adolescent or young adult who comes to a pediatrician probably comes with their mom, and Mommy is going to make them take the drugs.”

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