



The Right Call

Survival rates for teens and young adults with cancer are higher when they are treated at children's hospitals.

As a recent high school graduate, Heather Krich considered herself an adult. No way would she go to a children's hospital if she got sick.

Yet that's what happened after Heather was diagnosed with non-Hodgkin lymphoma and her doctors referred her to Seattle Children's.

They made the right call.

Studies show survival rates for many cancers such as Ewing sarcoma and acute lymphocytic leukemia are higher when teens are treated at pediatric hospitals and/or receive treatments developed specifically for children. At Children's, survival rates for many cancers, including non-Hodgkin lymphoma, Hodgkin lymphoma and brain cancer, are higher than the national norm.

"Looking back, I wouldn't have wanted to go anywhere else," says Heather, now 21 and an assistant teacher for children with special needs in the Northshore School District.

The latest therapies

There are several reasons why patients like Heather do better at children's hospitals than hospitals that also treat adults. The most compelling is that more patients at children's hospitals are enrolled in clinical trials for new therapies that are continually advancing the standard of care.

In addition, children's hospitals are more aggressive about treatment. That's because children are — except for their cancer — fundamentally healthy and better able to withstand vigorous protocols. Hospitals that



(Above) As a survivor of cancer in early adulthood, Dr. Becky Johnson (right) understands how difficult it can be to cope with a cancer diagnosis. Johnson and Leah Kroon, a clinical nurse specialist, have created a special program to provide pediatric treatments to adolescents and young adults with cancer.

(Page 4) For Heather Krich (at right, with oncology nurse Mandy Breedt), being treated for cancer on the same unit as young children was sad but inspirational. She recalls watching little patients ride tricycles up and down the hallway. "I realized I needed to stop throwing myself a pity party and start enjoying the time I have."

also treat adults gear their care to a more generalized population that doesn't tolerate such an aggressive approach.

Even when protocols are identical, studies show better outcomes in children's hospitals. It may be because pediatric hospitals rarely delay treatment if a patient isn't feeling well on a given day. Hospitals that treat the general population are more likely to wait because they are accustomed to caring for less resilient patients.

And those hospitals also have far less experience treating childhood cancers. When teens and young adults develop a childhood cancer, a children's hospital will be much more familiar with how to treat their illnesses.

The challenge is to make this age group feel welcome in a setting that also serves large numbers of young children. Our new Adolescent and Young Adult (AYA) Cancer Program aims to better meet the unique needs of teens and young adults.

Launched in 2007, the program is led by Dr. Becky Johnson, a pediatric oncologist who specializes in caring for adolescents and young adults.

"There's no good time to have cancer, but the teen years are particularly difficult," says Johnson. "Teens want independence. They're focused on school, friends and their futures. Cancer derails life's normal progress."

Contact with peers

Children's works hard to make younger patients feel comfortable in various ways, such as designing certain areas of the hospital around "balloon," "giraffe" and "whale" themes. But the hospital wants teens — and even people in their mid-20s — to feel comfortable, too.

"We're constantly asking ourselves, 'What can we do so adolescents and young adults feel as though they are in a place that was designed for them?'" says Leah Kroon, clinical nurse specialist for the AYA care team.

Now, clinic appointments for this age group are clustered on the same days and the program will soon offer



Tyler Tran, 13 (above with his mom, Amy), is being treated for acute lymphocytic leukemia. He appreciates that Seattle Children's Adolescent and Young Adult program connects him with other teens who are also battling cancer. "Things are easier to understand coming from another teenager."



activities and classes during clinic hours to help adolescents and young adults meet other patients their age. A revamped Teen Zone provides a place in the hematology/oncology inpatient unit to hang out, play games, watch TV and surf the Internet.

That contact with peers means a lot, says Tyler Tran, a 13-year-old Everett resident who comes to Children's for chemotherapy to treat acute lymphocytic leukemia. "You can tell somebody your story, and you can listen to their story," he says. "Things are easier to understand coming from another teenager."

Tyler got to know a teen from Hawaii who is also a leukemia patient. "He gave me advice about how to get through a certain type of chemo," Tyler says, "like bringing eyedrops because my eyes will get really dry."

Emotionally unprepared

Despite the advantages of treatment at pediatric cancer centers, only 38% of adolescents and young adults with cancer in Washington state are treated at Children's, Johnson says.

Yet many more should be — because outcomes are better and because children's hospitals are more attuned to their emotional needs.

Five-Year Survival Rates for Patients Ages 15 to 19 with Acute Lymphocytic Leukemia (ALL)



"Teens may appear to be ready to be treated as adults, but a lot of times they will regress emotionally to a younger age because of the stress of cancer," says Emily Sack, a hematology/oncology nurse. "They need a lot more support."

The AYA team is using data from a study completed in March by Amanda Breedt, another hematology/oncology nurse, to help develop the program. The study featured a survey and a focus group of patients between 15 and 22 years old.

"The thing that surprised me the most was how much adolescents and young adults want to come back to provide peer support and be mentors for other patients," Breedt says. "We're trying to figure out how to incorporate it."

Study results also made it clear that adolescents and young adults want education materials to focus on their specific psychosocial needs, such as how to prepare for school and what

to do about hair loss. They also want more information published online and presented by their peers.

Using social media

The AYA team is exploring joining a social networking site, such as Facebook, where it could publish cancer facts, post videos from former patients and provide adolescents and young adults a place to share their thoughts and experiences.

The team is also considering using text messages to answer patient questions and remind them about appointments and taking their medications — something this age group fails to do more often than others.

"The use of social media by this age group is unprecedented," Kroon says. "They are almost more comfortable communicating in this realm than they are face-to-face."

One of the most troubling effects of cancer treatment for adolescents and young adults is the potential

“Teens may appear to be ready to be treated as adults, but a lot of times they will regress emotionally because of the stress of cancer. They need a lot more support.”

— Emily Sack, RN

loss of fertility due to radiation and chemotherapy. The AYA program offers counseling to male patients about preserving sperm before treatment and will eventually offer similar counseling to female patients about preserving eggs.

“It’s a touchy subject and not everybody is comfortable approaching it, but we have a team that is trained to talk about it with patients and their families,” Sack says.

Many of the adolescent and young adult cancer patients who participated in Breedt’s study, including Heather, wanted to stay involved. Children’s is

organizing an AYA advisory board that can provide input into educational materials, facility changes and program development — and perhaps offer peer support to new AYA cancer patients.

“I definitely felt that a lot of things at the hospital were geared toward young children,” says Heather, “but after being treated there, I wish I could go to Children’s for my healthcare for the rest of my life and be riding the Balloon elevator when I’m 89.” ■



Pediatric oncology nurse Emily Sack (pictured above left with patient Kaitlin Basic and Kaitlin’s friend Sarah Kintner) knows how important communication is to making patients feel comfortable. “What we say when we walk into the room of an 8-year-old is entirely different than what we say to a 17-year-old,” she says.

Creating a Comfort Zone

Guilds are helping teens and young adults with cancer feel comfortable at Seattle Children’s.

The Seattle Children’s Hospital Guild Association is raising \$1.5 million to help the hospital better serve teens and young adults who are treated here for cancer.

The money will support the growth and development of the AYA program. A current project is looking at how community doctors refer teens for cancer treatment, which is the first step toward educating physicians about the benefits of using treatments developed specifically for teens.

The Guild Association is also helping Children’s create a more welcoming environment for these patients by adding age-appropriate décor, games and magazines to waiting rooms and to a teen room on the hematology/oncology inpatient unit. The Guild Association will also support group activities and outings for patients and the development of a Teen Advisory Board.