


Teens Do Better Here

Higher cure rates and fewer long-term effects from treatment are just two of the benefits teenagers and young adults up to age 21 receive when their cancer is treated at pediatric medical centers. Among institutions treating teens for cancer, Children's has some of the best survival rates in the nation.



Pediatric oncologist Dr. Blythe Thomson leads research studies that improve cancer treatments for teens and young adults and give them the best chance for survival. Institutions that treat adults often offer teens therapies that are better suited for older patients and that may be out of date with current pediatric cancer research.

LEFT TO RIGHT:

Treated for Hodgkin lymphoma at 14, Jaime Hitchcock, now 26, participates in a quality-of-life study in Children's survivorship program.

Mary Elizabeth Sierra-Lanham, 14, chatting with social worker Tanya Ranchigoda, says she appreciates staff members' ability to relate to teens.



WHEN MARY ELIZABETH SIERRA-LANHAM HAD HER EYES CHECKED FOR NEAR-SIGHTEDNESS, THE ROUTINE EXAM SHOWED THAT THE OPTIC NERVE IN HER RIGHT EYE WAS SWOLLEN. A STRING OF VISITS TO DIFFERENT SPECIALISTS LED TO AN MRI THAT FINALLY EXPLAINED THE PROBLEM — A LUMP IN HER HEAD WAS PRESSING AGAINST A MAJOR VEIN.

That was when mom Sally Lanham brought Mary Elizabeth to Children's, where blood and bone marrow samples confirmed that her daughter had acute lymphoblastic leukemia (ALL), a type of cancer where malignant white blood cells or "lymphoblasts" are overproduced in the bone marrow and can spread into the bloodstream and vital organs. ALL accounts for approximately 25 percent of all childhood cancer.

Although Lanham didn't know it when she switched Mary Elizabeth's care to Children's, her decision may have saved her daughter's life: Teenagers and young adults have a much better chance of beating ALL — more than 25 percent better — when they receive pediatric cancer treatments rather than those intended for adults. Separate studies in North America, France, Netherlands and Italy confirm these findings.

"We've learned from years of research that teenagers have far fewer relapses when their treatment is longer and more aggressive than the less rigorous treatment that middle-agers and seniors receive," says pediatric oncologist Dr. Doug Hawkins. "Yet, we still see medical oncologists in the community treating 15- to 21-year-olds with less effective protocols that are sometimes decades out of date."

Teens and young adults with cancer are better off when their family practice or internal medicine providers refer them to children's hospitals. They not only benefit from cancer treatments developed specifically for their age group, they also thrive in an environment where teams of skilled providers focus on their long-term health concerns and the unique needs of their entire family.

Reducing the risks

When a persistent cough and mysterious itchiness around the ankles sent 16-year-old Matthew Hale to his primary care physician, an X-ray revealed a tumor in the lymph nodes in his chest. Heeding the doctor's advice, the Hales drove to Children's that evening, where members of the cancer team met them in the Emergency Department and began a series of tests to pinpoint the nature of the tumor.

After a biopsy, clinical oncologist Dr. Blythe Thomson broke the news that the tumor in Matthew's chest was Hodgkin lymphoma, a type of cancer that can develop anywhere in the body's lymph system and can spread to the lungs, liver, bone or bone marrow.

Matthew was surprised when Thomson spoke directly to him rather than to his parents. But it's a strategy used by Thomson and her colleagues on the cancer care team that builds trust with teens and empowers them to take responsibility for their care.

"I was in shock about the diagnosis, but glad my doctor talked to me with my parents just listening," explains Matthew. "I prefer that."

The good news for teenagers with Hodgkin lymphoma is that cure rates are well over 90 percent. However, the treatment, which includes both chemotherapy and radiation, can leave teens with serious long-term effects, such as infertility, secondary cancers, or damage to the heart,

lungs and other organs that won't appear until 10 to 30 years down the road.

"I'm always thinking about what life will be like when the kids get older and trying to find ways to make the treatments less toxic right now," says Dr. Debra Friedman, an expert on Hodgkin lymphoma who currently leads several national clinical trials aimed at improving cures while reducing the long-term effects for teens who survive the disease.

Her current research tailors therapy to lessen the risks of toxicity for those in treatment. For example, some teens whose Hodgkin lymphoma responds quickly to chemotherapy no longer receive radiation. Those who respond more slowly to the chemotherapy still receive radiation, but at a low dose. Other slow responders get additional chemotherapy to boost cure rate and decrease the possibility of relapse — a situation that requires additional treatment and can cause more long-term effects.

For risks that cannot be mitigated, the cancer team works with patients to plan around them. For instance, teenage boys are encouraged to go to a local sperm bank so they'll have the option to father children later in life even if their treatment leaves them sterile. Most parents, says Friedman, strongly advocate the trip.

A healing environment

Lanham keeps a Web journal that chronicles her family's long journey with ALL — Mary Elizabeth, now 14, has been in treatment since August 2004. Lanham's weekly entries chronicle day-to-day details, including foods that Mary Elizabeth can tolerate, juggling schedules to get to appointments and her daughter's uncommon reactions to medications. Her journal reflects a truth about childhood cancer that is well understood by clinicians in pediatric institutions: when a child — even a teen — is sick, the whole family is affected.



I love you, stay away!

Younger cancer patients tend to flourish with the intense attention and specialized play therapy they receive during their treatment. But teens can flounder when their normal trajectory toward self-reliance is cut short with frequent hospital stays and health concerns that isolate them from peers. Child Life Specialist Katy Tenhulzen is a child and teen development expert who helps pediatric cancer patients of all ages cope with the hospital experience.

Tenhulzen supports teens in their struggle to maintain control and independence at a time when they must be dependent on parents and health care providers. She encourages journaling, scrapbooking, songwriting and creating art to help teens process what's happening to them and to make meaning of their cancer experience.

She also helps worried parents sort through common coping strategies of teen patients — sleeping to escape or being ambivalent about the future — and trains clinicians to create a culture of respect around teen sensitivities with body image, privacy and communication.

A host of specialists at Children's helps families cope with all aspects of the cancer experience. Physicians and nurse specialists work with patients and families to teach them about the disease and develop a plan of treatment. Child life specialists, social workers and chaplains support patients, parents and siblings throughout the emotional journey.

"There's a safety net of resources that's available," says Katherine Nelson Hall, whose 20-year-old son Brandon decided to transfer his care for Hodgkin lymphoma from a community oncologist to Children's. "When Brandon told his nurse practitioner about some nutritional issues he was having, she paged a nutritionist who was able to meet with Brandon immediately and give him suggestions tailor-made for a young man his age."

Mary Elizabeth recalls the MRI technician who played music and chatted with her during her first procedure at Children's — the visit that confirmed her cancer diagnosis. "I had an MRI at another hospital and it was scary," says Mary Elizabeth. "They left me alone and no one checked on me. At Children's, the staff tell stories and we laugh. I'll miss them when I'm done with treatment."

Surviving is just the first step

The experience of having cancer — and being treated for it — can have lasting physical and emotional consequences.

The Institute of Medicine, which is part of the National Academy of Sciences, recently recommended that survivorship programs be a focus of care for all cancer survivors.

Friedman directs one of the few survivorship programs in the country that follows teenagers who have survived cancer into their adult years. The program provides after-treatment clinical care and referrals, patient education, access to the most current cancer research and opportunities to participate in research to help others — all in a setting with providers who understand the needs of teens and young adults.

So in addition to the hugs and congratulations patients get from staff on the day that their cancer treatment is finally done, they also get a piece of paper that may be more important than their high-school diploma. It is a treatment summary that gives the exact details of their therapy, what is known about the long-term side effects, recommendations for future care and an invitation to Children's cancer survivorship program.

"By 2010, one in every 250 young adults in the United States will have survived a childhood cancer. They could potentially live another 60-plus years," says Friedman. "As pediatric oncologists, part of our job is to look beyond the cure and think about their immediate post-treatment needs, as well as those that will extend throughout their lives."

END

FROM LEFT:

Dr. Debra Friedman leads clinical studies to find the most effective cancer treatments with the fewest long-term side effects.

Matthew Hale, 16, describes his experience at Children's as "awesome" thanks to the positive energy of the nurses, their focus on pain-free treatment and their concern for his mom.

Reaching Out

Northwest families living far away from pediatric cancer care must weigh receiving treatment at home with traveling to Children's, which has some of the best outcomes for cure in the nation.

"That's not a choice we want families to have to make," explains Dr. Russ Geyer, the medical director of Children's Hematology/Oncology Department.

Patients in Alaska receive an initial evaluation at Children's, then get their treatment from a Children's pediatric oncologist practicing at Providence Children's Hospital in Anchorage through a program set up by Seattle Children's, the Alaska Native Medical Center, Providence Children's and the state of Alaska. They are also encouraged to join a dedicated survivorship program after treatment, which is affiliated with Children's after-care program.

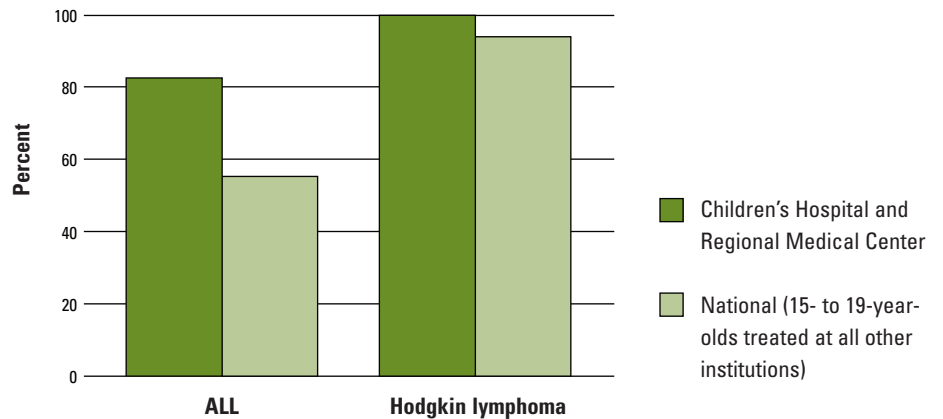
Patients receive the exact same protocols and rigorous safety standards followed at Children's, with one exception — each step of their treatment plan is double-verified by fax instead of in person. Geyer and his team are working to set up a similar relationship with providers in Montana.



Dr. Russ Geyer

Five-Year Survival of Cancer Patients, Age 15-19

Diagnosed 1996 Through 2002



Proven Outcomes, Newest Treatments

Children's is dedicated to research because it improves our ability to successfully treat cancer.

Children's helped create — and remains a leader in — the Children's Oncology Group (COG), a group of 240 pediatric medical institutions that integrates treatment improvements gained from previous studies while exploring new treatment options.

More than 97 percent of the cancer patients who participate in clinical research studies are children treated at COG-affiliated institutions, which is one reason why survival rates are so much higher for patients treated at pediatric medical centers.

Children's was recently awarded one of only 15 spots in an elite COG consortium that studies better ways to control secondary symptoms brought on during and after cancer treatment — an honor that recognizes our contributions in the area of cancer survivorship.

Social worker Tanya Ranchigoda is one of the many specialists who help patients and families cope with the physical and emotional issues that arise during their battle with cancer.

