

Please note chemotherapy and radiation have never been subjected to clinical trials for approval for use on children - CW

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TJ Colby reads out loud while his Special Ed Instructor Deborah Cockett follows along. TJ was diagnosed with leukemia at age 2. Intense radiation to his brain has left him with severe learning disabilities.

Lingering effects

The chemotherapy and radiation that saves children from cancer also kills brain cells and can cause lifelong learning problems

By Katherine Nichols
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TJ Colby was diagnosed with leukemia at age 2. For his grandmother, Mina Humphreys, words fail to describe the nightmare that ensued. "It was horrible," she said simply. And his relapse at age 5 was "even worse."

The family longed for a return to their standard, pre-cancer routine -- and a year later chemotherapy and cranial radiation did cure the cancer. But there were side effects: Learning and behavior problems brought on by the treatments themselves.

"It was probably the hardest hit of all when I realized that we were never going to get back to normal," Humphreys said. "There was going to be a 'new normal.' I cried for a week."

Humphreys understands well the denial that most parents harbor after experiencing the horror of watching a child cling to life. During TJ's second round with leukemia, Humphreys estimated he visited the hospital 20 times over three years. The first stay lasted 11 days. When he finally recovered, learning disabilities, short-term memory loss and other issues emerged.

"The day the treatment stops, the child is faced with a whole new set of problems, and these are problems that can go on for the rest of their lives," said pediatric oncologist Dr. Kelley Woodruff, a clinical faculty member of the Cancer Research Center at the University of Hawaii.

Recovery is relative. Cancer and its treatment "change aspects of the child's life forever."

Statistics vary, but medical literature estimates that a third of all young cancer survivors suffer from cognitive, social and emotional impairment due to the lasting effects of a chronic illness and the debilitating treatment to cure it. Patients under age 8 are affected more than their older counterparts.

This is why Humphreys and other volunteers associated with the Hawaii Children's Cancer Foundation are applying for grants and raising funds to begin a Cognitive Remediation Program by the end of the year. The program would include evaluations by a pediatric neuropsychologist, and individualized strategies to improve their academic performance, hopefully "making school easier, which will improve their self image," said Humphreys.

Mari Galiher, a 13-year-old who just finished eighth grade at Iolani School, remembers when dark bruises started forming on her legs in pre-school. During the two years of treatment that followed her leukemia diagnosis, she was often nauseated and fatigued. "I really wanted to play, but I couldn't keep up," she said.

Now in remission, Mari is dealing with a second set of problems, including Attention Deficit Disorder, which requires daily medication.

She stays active in class discussions, dutifully seeks extra help after school, takes dance lessons and plays softball and basketball, and offers encouragement to other kids battling cancer. Even so, organizing and processing new information is a constant challenge.

Mari's mother, Diane Ono, noted that Mari had 15 or more treatments to her central nervous system. "So you can imagine that this would do something to your brain."

Ono, who works part time as an attorney, ends her term as president of the Hawaii Children's Cancer Foundation this month, but will continue grant writing for the nonprofit organization. "I'm passionate about (my volunteer work) because of what Mari's gone through. While we were in the hospital with her, I told myself, 'If we come through this, I'm going to try to help others.' "



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TJ Colby, with Deborah Cockett, his special ed instructor at Lanikai School.

Leukemia is the most common type of childhood cancer, said Ono. "Seventy-five to 80 percent of kids are cured today. But it's not without problems." It is well-documented that chemotherapy and cranial radiation kill cancer cells. Indeed, the alternative to treatment is death. Unfortunately, this therapy can also destroy growing brain cells.

In Hawaii, approximately 40 children and adolescents are diagnosed with cancer each year, according to Woodruff, though some sources report higher numbers. Because the regimen takes about two years, more than 200 children can be in treatment at any given time.

Robert Butler, a leader in the field of cognitive remediation in children, spoke to a local group of cancer survivors and their families in April about starting a program.

"We're working very hard to teach kids how to manage their own abilities," said Butler, a psychologist at Oregon Health and Science University who has studied brain injury rehabilitation in children since 1990. Rather than focusing on specific academic subjects and special education, he gives students techniques to improve their concentration and cognitive function.

The difficulty with kids who have survived cancer is that "very commonly they look like they're paying attention, behaving correctly, not getting out of their seat and not disrupting class," said Butler. Because many problems remain undetected until an academic crisis illuminates them, the number of children suffering from post-treatment issues may be much higher than reported. This is why evaluations and early intervention with practical

solutions are so important.

The road leading to these attention and learning disabilities is a harrowing one. Because nobody wants to leave a seriously ill 4-year-old alone in the hospital, one parent must be with the sick child at all times. Neighbor island families are often separated. Two-income couples often sacrifice one parent's job. Many get behind on bills. Average out-of-pocket expenses can amount to about 53 percent of a family's gross income. Healthy siblings are neglected and suffer in their own ways, fueling parents' guilt. "It's just a mess," said Humphreys.

The Hawaii Children's Cancer Foundation helps with education, advocacy and financial support, and is working to bolster its \$200,000 annual budget so that it can also help families during the difficult years after treatment. The Cognitive Remediation Program will cost between \$5,000 and \$7,000 per child.

Families are often unprepared for the agonizing struggle ahead in school -- and in life. Some children might have difficulty focusing. Others could be so severely impaired that they will never live independently. "Honestly, some parents don't even know that their kids are going to face this," said Humphreys.

One of those parents was Humphreys' daughter, Jenny Colby, the mother of 11-year-old TJ and two daughters, ages 7 and 6. She recalled that TJ was a happy child until he started falling constantly, and begging to be carried. Fevers rose to 104, then disappeared quickly. Bruises wouldn't fade. After his diagnosis and treatment, he relapsed. Time out of school for extensive treatments -- along with the effects of those remedies -- forced teachers to hold him back a grade.

Jenny Colby said that TJ may be able to solve a math problem on a Tuesday, but can't do it again on Wednesday -- and might not notice this unless someone tells him.

"It makes me feel really shocked and really embarrassed," he admitted.

Money and a toy cash register (and some real-life practice at 7-Eleven) make math a little more fun, but his special education teacher, Debbie Cockett, said that "some days he knows it, and some days he doesn't."

Transitions from one activity to another can also prove difficult. And "if he does too much work, his brain kind of goes into overload," added Cockett. His fourth-grade special education class at Lanikai Elementary School allows him to proceed at his own pace, and take breaks with Bugs, the resident rabbit.

On a typical day at school, TJ works alone in a room apart from his

classmates, but joins them at intervals for P.E., art, music and lunch. Cockett corrects him as he reads aloud from a third-grade book. Though he stumbles occasionally, his inflection and comprehension are impressive.

When asked how he feels about his reading, TJ reports, "Good." He gamely chats about playing outfield on the baseball team ("I don't get a lot of action"), the soft place he has in his heart for Tyra, his German Shepherd, and his plastic wrist bands honoring friends with cancer.

Does he recognize that he has trouble focusing? "Yeah, sometimes. The treatment damaged something in my brain. It's very hard for me because I can barely remember things."

Though he also struggles with subtle social cues, he's famous for his powerful hugs, and friendships remain strong, said Cockett. "Everybody loves TJ. He'll give away his last juice, his last quarter. He's Mr. Aloha!"

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