

Hospice program lifts sick children, families

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Interior designer Robin Zarzecki jumped at the chance to paint a fiberglass butterfly last year for the Wings in the City, a public art project benefiting Wings, the BJC pediatric hospice and palliative care program. But that doesn't mean it was easy.

"I was crying and sketching and sketching and crying," said Zarzecki. "Caleb was with me as I did this."

Caleb was Zarzecki's son. He died of cancer in 2008 at age 15. The family's home in Troy, Ill., is filled with projects Caleb created with Wings expressive therapist JJ Tellatin.

Zarzecki attached drawings of angels by Caleb and other sick children to her butterfly and painted it turquoise — Caleb's favorite color.

Zarzecki's butterfly was installed this week outside Macy's at Chesterfield Mall. Other butterflies have touched down in the Central West End, Kiener Plaza, Tower Grove Park and Clayton. The sculptures, 56 in all, will remain on view until a benefit auction May 21 at the St. Louis Hyatt at the Arch. The goal is to raise \$1 million to benefit the Wings expressive therapy program.

Zarzecki hopes the whimsical butterflies will change perceptions about hospice and palliative care.

"If we can help parents take those last days and live with their child instead of die with them, it's a gift we have to give," said Zarzecki. "That's why I wanted my butterfly to be bright. Hospice is not sad, it's just necessary."

'IT'S FREEDOM OF EXPRESSION'

Not all patients in the Wings program are dying, but they all have a life-altering illness. Willy Lee enlisted Wings when her 12-year-old son, Will, was diagnosed with a form of leg cancer in November. And though Will is responding to chemotherapy, he cannot attend school.

"Before this he was into skateboarding, BMX, mixed martial arts and football — basically anything physically dangerous," said Lee. "We just thought he had injured his leg."

Wings provides a spectrum of services from nurses who help patients manage pain to pastoral advisers who offer spiritual counseling to volunteers who run errands. The program also includes expressive therapists who use music, art, storytelling, puppets and other tools to get families to confront their feelings. Lee didn't know how crayons and clay could help, but she figured Will and his little brother, Malcolm, deserved some fun.

Expressive arts therapist Janet Tellatin started visiting the family every few weeks to work on different projects. During a visit last month, Will showed Tellatin a mask he painted and started work on a life map that highlights favorite memories. "Like when I hit myself on the face from jumping on the bed," he said laughing. "That was crazy," answered his big brother, Ryan, rubbing Will's head. "You've got some fuzz there. It's coming back."

Laughs and hugs are common in the Lee home, but that's not always the case, Tellatin said. "A lot of times the kid is protecting the parents and the parents are protecting the kid, so there is often silence," Tellatin said. "Everyone is in their own room, and they aren't going there. Creating connections is the goal."

Lee says Tellatin's visits have helped her typically reticent son open up. "I'm hearing a lot more 'thank you's' and 'I love you's.' Those of things we don't normally hear," said Lee. "I thought they would come and do art just like at school, but it's not art class. It's freedom of expression."



Left) Willy Lee gives her son Malcolm Lee, 9, a hug after an expressive arts therapist finished a session with the family at their home in St. Louis. Malcolm's brother William is fighting bone cancer and the family is receiving help from the therapist through Wings, the BJC pediatric hospice and palliative care program.

Right) Malcolm Lee, 9, and his brother William Edwards, 12, center, talk with expressive arts therapist Janet Tellatin during a session with the family at their home in St. Louis. William is fighting bone cancer and the family is receiving help from the therapist through Wings, the BJC pediatric hospice and palliative care program.

FAMILY CONNECTIONS

Like Lee, Zarzecki considered expressive therapy a diversion. When Caleb was diagnosed in 2002 with brain cancer, he was too sick to play outside or make trips to the Magic House or zoo.

"He was so isolated," said Zarzecki. "I wanted to introduce him to things he could do at home that would make him feel like a kid again."

But Tellatin's games gave Zarzecki's family a new vocabulary to talk about the hard stuff.

"They found things he liked to do and ran with it," said Zarzecki. "I'll never forget the day the therapist came with a big bucket of sand with these figurines he liked to play with. But they weren't superheroes; they were angels and tombstones and he was able to get in there and play and talk about scary monsters and what he thought heaven was going to look like. I would come in at the end of the session and he could talk to me. We could have an open discussion and connect without having to say, 'Caleb, you're going to die.'"

Zarzecki had just learned she was pregnant when Caleb had a seizure on Easter Sunday in 2008. The doctors at St. Louis Children's Hospital discovered a cluster of brain tumors. They could not save him, but they could buy the family a few days.

"That turned into 13 weeks," said Zarzecki. "We brought Wings in immediately."

Tellatin returned. Caleb told her how he was worried he would not meet the baby sister his mother was carrying. Zarzecki and Caleb already had decided her name would be Bela Cate — Bela and the "C" in Cate is Caleb spelled backward.

"She was able to pull out of him what he wanted to say to her and together they wrote a letter to Bela," said Zarzecki. "I read that to her all of the time, and she knows her brother."

Caleb's younger brother Luke, however, benefited from the program in ways Zarzecki never imagined. At the time, Luke was not into art or creative writing. Still, he and Tellatin connected.

"He could ask questions he couldn't ask me, like, 'How is my brother going to die?'" said Zarzecki.

Tellatin says her first job is to be present.

"I tell them you don't have to talk, you don't have to do any of this," said Tellatin. "But we're usually welcome especially by siblings who, as hard as their parents might try, sometimes feel left out."

On June 30, 2008, Luke woke up and gave his brother a kiss. Caleb — Zarzecki believes he was waiting for Luke's goodbye — died moments later.

Then Luke asked for pancakes.

"It was amazing. He knew Caleb was OK now and JJ was the one who got him to that place," said Zarzecki. "The nurse goes in the kitchen and realizes we didn't have what we needed. She goes, 'Luke, let's go to McDonald's,' which gave me and my husband the time we needed. It was the big things and a lot of the little bitty things Wings did I will always be grateful for."

MANY, MANY ANGELS

Tellatin is touched when she sees the artwork she helped children create at funerals and on living room walls. She keeps copies herself -- a picture of a girl flying out of her wheelchair drawn by her sister, a poem titled "Dear Stinky Lungs" by a girl who died of cystic fibrosis, autobiographies by children struggling to find meaning in their short lives and many, many angels.

"You hear that a lot from children," said Tellatin. "They see angels and spirits and relatives. In many ways, working with children is easier than adults. The kids have fear, too, but they are so much better at being in the moment," said Tellatin. "When you're young you don't have the sense that death is bad. They see a dead worm and it's just dead. Play and imagination come so naturally to them, and it's safe for them to go into that imaginative world and talk about how this animal or toy is feeling."

Tellatin has worked with sick children for 20 years and has three children of her own. Everyone wants to know how she does it. "I get that all of the time, but it's such an honor working with these kids because of the amazing things they do," said Tellatin. "To me it's very powerful to help these children find meaning — to show them what great teachers they are and how much they show us all about gratitude and life."



Rich Brown, left, and Keith Skaer, both of BJC, install a Wings in the City butterfly on Maryland Plaza in the Central West End on Wednesday. Fifty-six butterflies will be on display throughout the metro area to raise awareness of Wings, the BJC pediatric hospice and palliative care program. The butterflies will be auctioned off at a benefit for Wings on May 21.

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