



A Place To Say Goodbye

For children like Caitlin Dolaghan, in the final stages of life, a remarkable hospice just for kids provides love, comfort —and even joy

GETTING THROUGH THE DAY Having cancer “was too much for me to handle,” says Caitlin (at the hospice, left, and being examined by a nurse, above). “Not holding my feelings in makes things better.”

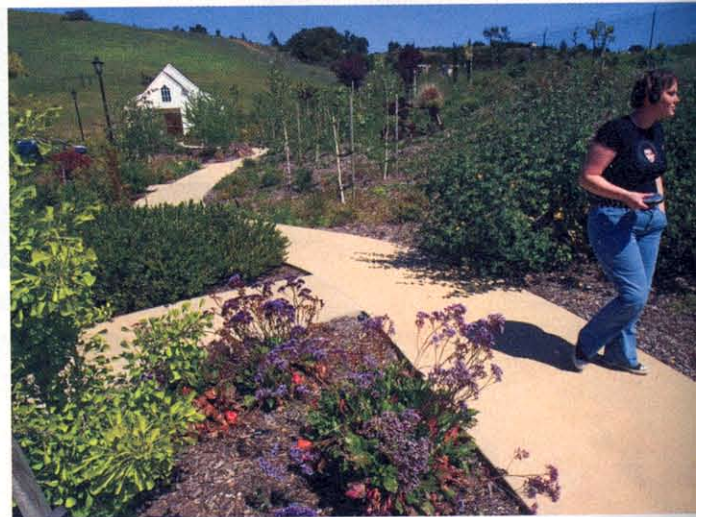


PERSPECTIVE “I never had a philosophy of life,” says Caitlin (with pet chick and walking the hospice grounds). “Now I think we should make the best of the time we have.”

Aren’t they cool?” says Caitlin Dolaghan, reaching into a clutch of speckled 13-day-old chicks and gently slipping one back into its blue plastic crate. At 18, she’s every bit a typical teen: Goth eye makeup, Johnny Depp T-shirt, the ever-present CD player blasting Evanescence. She dreams of a career in rock and roll—“Not for all the fame and stuff,” she says, “just to play the music.” But for all her bravado, Caitlin is a realist: She knows that the fluffy chicks she’s playing with are, in all likelihood, going to live longer than she will.

After a string of symptoms that began with a pain in her leg, Caitlin was in seventh grade when she was told she had metastatic osteosarcoma—bone cancer. Today, despite almost five years of aggressive surgeries and chemotherapy, she has an inoperable tumor growing into her pulmonary artery that could rupture at any time, killing her within minutes. Doctors say she will almost certainly die of it. “Sometimes I just feel panic coming over me,” she says. “I can’t run away from it. There’s no place for it to go.”

Staring straight into one’s own mortality is a tall order for anyone, let alone a kid who doesn’t have her driver’s license yet. Caitlin has slowly begun to accept the fact that she is dying—even as she holds out hope for a miracle. But she is adamant about one thing: She will not undergo any more medical treat-



ments. “What’s the point of getting another MRI when there isn’t anything more they can do?” she says. For now she struggles to get on with her life, attending her prom last May in a gown inspired by *The Lord of the Rings* and graduating with the rest of her class, despite a coughing fit that began right before she crossed the stage to collect her diploma. As full of contradictions as any adolescent, she bristles when asked about her plans for the future. “I just don’t know what to say,” she says. “I don’t know what’s going to happen.”

Their journey has been harrowing, but Caitlin and her family have found friends along the way at the George Mark Children’s House, the country’s first freestanding pediatric hospice dedicated to helping kids and their families deal



A MOTHER'S HEARTBREAK "Seeing your child go through this is difficult at any age," says Carol of Caitlin (at home with her oxygen tank). "That is very hard on me."

with untimely death. Housed on a five-acre compound in the foothills of San Leandro, Calif., the hospice has a unique mission: "to make the process of dying the least traumatic it can be, for children and their families," says Dr. Barbara Beach, 56, a pediatric oncologist who founded the center last year with child and family psychologist Dr. Kathy Hull, 62. "But we're not about dying here; we're about living. Here we live until we say goodbye."

When 11-year-old Adis Bajrami was admitted with a brain tumor in August 2004, his doctors didn't expect him to live 48 hours. But nurses at George Mark improvised an alternative to an open IV port for his meds, allowing him to do what he loved most—splashing in the oversize hot tub for hours. No one can say if there was a strict medical benefit, but Adis went on to live another six weeks.

The hospice staff provides a strong shoulder to lean on for parents exhausted by the stress of providing round-the-clock care. When Mike and Jamie Meringer's baby daughter Riley Jane was diagnosed with a rare form of adrenal cancer, they were told by a staff member at one hospital that since she would likely hemorrhage in death, "we should buy dark towels so the blood wouldn't be so obvious, and to get our oth-

er child out of the house so he wouldn't be traumatized. That was it. They sent us home," says Jamie. Torn by stress over Riley's illness, the family began to relax within hours of arriving at George Mark. Laundry and meals were taken care of; Mike, a tech-firm executive, could check his e-mail using the hospice's computer. "They took care of everything so we could focus on what really matters," says Jamie. Riley died six weeks later—peacefully, in her parents' arms. "There are lots of people to tell you how to bring a child into the world, but very few who can help you escort one out," says her father.

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MIKE MERINGER, PARENT

The George Mark hospice, named for the two deceased brothers of cofounder Kathy Hull, houses eight light-filled rooms for kids, decorated with murals in jungle, cowboy or princess themes, and two apartments where families can stay for days or months at a time. There are flower gardens, an enclosure for visiting pets and, on a hill behind the main building, a spare, high-ceilinged chapel decorated

with a simple Quaker spinning wheel.

The cycle of life symbolized by that iron circle has played out 17 times since the home opened its doors in March 2004. Seven-year-old Crystal Gonzalez was diagnosed on her sixth birthday with a malignant brain tumor. "The hospital was scary. She was depressed," says her grandmother Georgina Torres. But after a doctor sent them to George



Angels are displayed at the hospice when a child near death is in residence

Remembering Junior

Like many dying children, 16-year-old Jairo “Junior” Garcia’s greatest fear was that he would be forgotten. Junior, who suffered from cystic fibrosis, had been at the hospice for a month; in May of this year his temperature spiked. His parents got him into a cool shower and helped him put on his favorite pajamas. “He knew sign language, and when he climbed under the covers he signed to his two sisters, ‘I love you guys,’” says his mother, Melvi Franco. “He went to sleep peacefully and started breathing heavily.

I got in bed with him. We called the family. They all got to say goodbye. I was holding Junior in my arms. I could feel his heart beating, and then it stopped. It was a sunny day, Memorial Day. That whole day we said, ‘Junior chose this day. He wanted to go out a hero.’” Below, excerpts from an essay Junior wrote about a year before he died:



Normally, I am sick all of the time. If I am healthy it is only for a couple of weeks after a lot of antibiotics. I have never been out of the hospital for more than five months—that was when I was really young.

I think my illness has made me a lot stronger as a person . . . also a lot wiser than I would have been if I didn’t have it. I always try to be as positive as possible. My mother says that my health is much more important than my schoolwork any day. I don’t always believe it but I have learned to trust my mother. When I am in the hospital doctors and nurses always like to play chess with me. When I am sick, *The Simpsons* always makes me laugh.

Overall, I think I turned out all right. I think my parents will be proud of whatever I become.

Mark, Georgina saw a change. “She called me up and said, ‘Oh, Mami, it’s so *grand* here. There’s plenty to eat and you don’t need quarters for the laundry machine!’” Crystal loved playing dress-up, says Georgina. “Her colors were pink and purple, so one of the nurses gave her a pink crown that she loved to wear.”

But her greatest joy came when she met 8-month-old Riley Jane Meringer, whose medication, like Crystal’s, caused abnormal swelling and hair growth on her body. When Crystal first saw Riley, “there was a look of such awe on her face,” says nurse Christy Torkildson. “Riley was her baby from then on. She whispered to me, ‘I never *knew* anybody who looked just like me before!’” Crystal would share her toast

with Riley, who liked to clamber into her bed. “They’d sit there for the longest time while we read them a story,” says Torkildson. “Eight months old and 7 years. But you’ve heard the term ‘soulmate’? That’s what they were.” Three days after Riley died, Crystal attended her wake. “I suspect she was thinking the same was going to happen to her, but she would never say that,” recalls her grandmother.

The hospice’s entire staff cared for Crystal during her five-month stay. “Toward the end she gave her toys to her little sisters and her umbrella to me,” says Georgina. “She said, ‘Mami, I can’t walk anymore, and I’m never going to be able to use it again. I want you to take it.’ I was sad, but sometimes when I couldn’t sleep, I would run into a nurse or assistant in the hallway, and they would put their arm around me and say, ‘It’s okay. Crystal will be in heaven soon.’”

On Sept. 8, 2004, three months before her eighth birthday, with her father and grandmother at her bedside, Crystal entered the final phase of her life on earth. When she began to show “terminal restlessness”—agitation that sometimes appears as death approaches—nurse Roberta Davis administered sedatives. “Then Crystal calmed down,” says Georgina. “I put my head on the bed and fell asleep. Suddenly I felt a soft breath next to my ear. I looked up, and Crystal was quiet. I knew she had died.”

Afterward, dressed in her favorite Hello Kitty nightgown, Crystal was wheeled in her bed up the walkway to the sanctuary. Two days later, her hair freshly brushed, wearing her pink crown and surrounded by vases of wildflowers picked by the staff, she was the star of her own memorial service. “When she could still talk, she’d say, ‘I’m afraid you’re going to forget me,’” recalls Davis. Crystal’s little sisters paid tribute by singing the alphabet song, and “everyone in the room sang with them,” recalls hospice communications director Annie Berlin. “Crystal had the funeral of a princess, just like she’d dreamed: standing room only.”

No one at the hospice—where families are asked to pay what they can, with the rest covered by private donors—considers caring for dying children to be easy. “At home I have five horses, three dogs, two cats and a pig,” says Davis. “The way I get through the sadness is, I go into the stall and hug my pig. That sounds strange, but that’s where I went after Crystal passed



A FATHER'S LOVE "The bottom line is Caitlin wants to live," says John (with her and Carol). "My understanding of who God is means he does perform miracles. We pray for that."

away. That's where I cried." And in the future, where she'll likely cry again. Unlike little children, dying teenagers often react with anger, says Beach: "It's like they've been led into the best candy store on earth, urged to see and smell everything, and then we say, 'You can't have it.' It's a rip-off."

Caitlin so far has chosen not to live in the hospice full-time, but her connection to it has helped her family navigate waves of shock and denial. Early on, there was tension with her mother, who felt that Caitlin wasn't accepting the bitter reality of her prognosis. "What was really bad were those days every parent of a teenager has when they're just being a stinker," says Carol. "I found myself thinking, God, please don't let her die on a day like this."

Adding to Caitlin's worries is the fact that her father, John, is battling Parkinson's disease. She draws strength from his advice: "He told me he won't give up if I don't." In recent months her anger seems to have ebbed. Asked to name the happiest memories of her life, she brightens: the food fight she started at a family wedding; the family trip to the Sierra Nevada Mountains this summer, when a bobcat walked "right by our cabin window—it was neat." She and her mother are on better terms too. "I guess my mom thought I wasn't accepting the prognosis, but I was," says Caitlin. "She just didn't

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CAROL DOLAGHAN

understand that I could also hope." Carol says there are things she would do differently today. She recalls one day when Caitlin learned that her cancer, after a period of remission, had returned. "We were driving home, and she was pounding her fist and yelling. I told her, 'That's not going to help anything.' Now I'd say, 'Yell all you want.'"

Within the last few months there have been a few episodes when Caitlin suddenly began coughing up blood. "We were all thinking, This could be it," says Carol. "At first she panicked."

But the bleeding subsided. According to one nurse, when Caitlin's death does come, "it will be very quick, and there are things we can do to keep her comfortable." Still, Caitlin is understandably fearful about what those final moments will bring. Sometimes in her dreams, "evil cartoon characters are chasing me," she says. But there have been other kinds of dreams in

the night as well, including one prompted by nothing she can quite put her finger on. "I'm standing on a really high place, like a mountain, and I throw my arms open as wide as I can. And then, all of a sudden, I'm *flying*," she says, with just the hint of a smile. "You know, like Peter Pan."

By Susan Schindehette. Vicki Sheff-Cahan in San Leandro and **Johnny Dodd** in Los Angeles

For more information about the George Mark Children's House, visit www.georgemark.org or call 866-897-4624.