

HELPING HANDS

From the beginning of our work in palliative care, we have believed that the mission—relieving suffering in those who are ill—can be accomplished only when patients and communities insist that excellent palliative care be provided by the professionals and institutions to which they turn for help. The passion that arises from the experience of caring for a loved one in need drives the changes that must occur. In that sense, patient and community advocacy and activism are palliative-care core values. In pediatric oncology and palliative care, the Valerie Fund stands out as an exemplar for such a value. The featured article in this month's "Helping Hands" is written by Valerie Fund cofounder Sue Goldstein. In an excerpt from her upcoming book, *Unexpected Lives*, Goldstein describes one aspect of the family caregiving experience, the intensity of the experience of time. On the Valerie Fund Website, there is a quote from Mark Twain—following the death of his own daughter—in which he beautifully captures the same type of attitude that drove the creation of the Valerie Fund in 1976 and helps us all to persist in our efforts to continually improve care: "I bear it as I bear all heavy hardships that befall me: With a heart bursting with rebellion."

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The Hall Clock

by Sue Goldstein

January 1972

I saw Valerie—and the hall clock—as I raced from the elevator onto the eleventh floor of Babies Hospital. A wisp of a child, she stood with thin arms laced across her narrow chest and a comic frown transforming the small impish face. Traffic into New York City had been heavy. I was five minutes late and in trouble. My five-year-old made this obvious as she pointed to the large black-and-white clock above the hall doorway. She knew exactly what she was doing. That clock was a tyrant with unyielding power, indifferent to all who passed by. I was no match for either one: my daughter or the clock.

The rebuke dragged on. Valerie's foot, tapping dramatically on the drab linoleum floor, punctuated her shout: "You're late, Mommy. Where were you? I've been waiting!" It was a few minutes after ten on Wednesday

morning. Val was in her Donald Duck nightgown. Faded and permanently stained with finger-paint from the hospital playroom, it was much too big for her, but the down-to-the-floor pink nightie was loved beyond reason.

Her emerging smile quickened to a giggle and then, bursting with nervous laughter, she ran to me. I caught her in my arms and held on tight, repeat-

ing over and over, "SorrySorrySorry." And I was never late again, regardless of traffic. I got up earlier, spent a little less time with her older sister, Stacy, hurriedly prepared a sleepover's worth of goodies, and called upon my rides—friends who carpooled for my trips into New York—to speed.

Valerie was three when the diagnosis of Ewing's sarcoma shattered our family. Scary surgeries, chemotherapy, side effects, and unplanned trips to the New York oncologist or, closer to home, the emergency room at Overlook Hospital, kept us agitated, uncertain, and separated from the normal existence our friends seemed to enjoy.

Hospitalized at the end of her two years of chemo for three days' worth of medical testing, Valerie appeared stoic about the overnights. She didn't complain, but misery resided in her eyes; they followed me everywhere that first night as I unpacked her favorite blanket and pillow. Val's stuffed lion completed the picture, its worn body leaning cockeyed against the metal bed rail. It made her hospital room seem more homelike, but my little girl didn't smile. *Oh, God. What will they find this time? Nothing. Nothing.*

Val knew the nurses on the floor from past inpatient stays and most catered to her whims. Since hospital rules at the time prevented parents from sleeping over, the night staff assumed a surrogate's role. Some handled it better than others. A widespread belief existed—and I, for one, was a believer—that the nurse in charge of your child was special, that she was a kind and loving stand-in.



Friends or relatives would pick me up at our home in Warren at 9 a.m. after I saw Stacy off to school, and usually dropped me off at the hospital before 10, well ahead of Valerie's first tests in the morning. The two of us would face unfamiliar medical staff, strange procedures, and weird equipment together. On that particular Wednesday, medical orders required us to roam the subterranean level of the institution, a tangle of tunnels that gave us indoor access to the facilities making up the whole of Columbia-Presbyterian Medical Center. Our goal was Nuclear Medicine at the Neurological Institute, more than an underground city block away.

Our journey began with Val, wrapped in a blanket, a pillow behind her shoulders, sitting in an archaic wooden wheelchair. With me pushing, we took the elevator down and exited into a subsurface world of high-ceilinged passageways, their concrete walls painted a gloomy ashen grey. Poor lighting heightened the dismal atmosphere and allowed warped shadows to lead the way. As we moved along, I chatted with my daughter about her latest artwork, a lopsided papier-mâché pumpkin awaiting completion in the hospital's playroom. My mind's eye, though, kept close watch on the path ahead, spotting hazy, otherworldly figures beyond every corner, figures that vanished as we approached. Valerie didn't seem to mind. Enjoying the action, she begged me to push faster. I needed no encouragement and barely controlled the urge to run.



Once back in her room, I'd spend the medical downtime with Valerie watching children's TV, reading to her, picking Play-Doh out of her hair, and following her commands. "Mommy, I want some juice/a

cookie/Captain Crunch/wonton soup—with only one wonton, Mommy." The soup required a trip outside the hospital to a nearby Chinese restaurant. Mostly, though, I ran marathons up and down the halls of Babies. I was not alone. Other mothers ran beside me.

My husband, Ed, joined us at the end of his work day and was welcomed as member No. 2 of the aide brigade. He and I took turns following orders. Every so often, I sat out his turn in the parents' lounge—when Valerie gave me permission—feet up and drinking my home-brewed iced tea.

Prolonging visiting hours well past the limit was common for us, but finally we'd be forced to give Valerie a last hug and kiss goodnight and tuck her in. She knew that I

About the Valerie Fund

The Valerie Fund supports pediatric oncology centers at Overlook Hospital and Morristown Memorial Hospital, as well as six other hospitals. The Fund's mission is to support comprehensive healthcare services close to the homes of children with cancer and blood disorders. The Fund is a not-for-profit organization established in 1976 in memory of nine-year-old Valerie Goldstein by her parents, Ed and Sue. The eight Valerie Fund Children's Centers for Cancer and Blood Disorders provide care to more than 5,000 children and their families each year, comprising the largest network of healthcare facilities for children with cancer and blood disorders in New Jersey and one of the largest in the nation.

For more information on the Valerie Fund, visit www.thevaleriefund.org.

Liam's Room

As the fight against pediatric cancers and other diseases rages on, so too does the drive to create nurturing resources for sick children and their families. One new initiative which has risen from a local family's grief, caring, and commitment is Liam's Room. A nonprofit organization established in recent months by Lisa and Peter McNamara in loving memory of their two-year-old son, Liam, the forces behind Liam's Room are currently working with Overlook Hospital to design a special room in the hospital's pediatric inpatient unit. The room, to be used by families whose children are diagnosed with a chronic or life-limiting illness, is intended to provide as many comforts of home as possible during a child's hospital stay. The initiative also provides for staff education in pediatric palliative care and additional supports and resources for families.

For more information about Liam's Room, visit www.liamsroom.org.

would return the next morning, no later than 10, with a suitcase filled with cookies, little toys, and get-well cards from schoolmates. Leaving her room at night, Ed and I would rush from the eleventh floor to our car for the hour's drive back home to New Jersey. We needed to tuck Stacy into bed. We made that deadline more often than not.

And, in almost every way, time was measured by the clock on two simple dimensions: illness-based and non-illness based. When Val was diagnosed with bone cancer, Stacy, my healthy child, was abruptly thrust into the background. It was neither my intention nor my desire. I worried about her when we were apart, hurried back to her as soon as possible, and yet, when by her side, yearned to be with her sister. Such were the demands involved in caring for the seriously chronically ill child. But that's how time worked, so precious and so scarce.—Adapted from the upcoming book *Unexpected Lives*, by Sue Goldstein.

For more information on the Palliative Care Program, contact Jeanne Kerwin at (888) 411-9697.