

Dear Friends,

Nothing is worse than the loss of a child, unless, perhaps, the loss of a parent at a young age. We at Healing Environments are dedicated to being there for you in your darkest hour—the life-threatening illness of a child or a young child’s parent is indeed one of life’s darkest times.

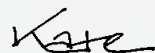
We at Healing Environments often feel guided in our work and this year we felt compelled to reach out with hope and healing for those of you in such a situation of potential loss. We were inspired by instances of loss in our own lives, as well as by three of the greatest films of all time, *The Apu Trilogy*.

Pather Panchali was the first film of a now famous Indian director Satyajit Ray. In timeless black and white images, it follows the life of a poor Indian boy through childhood and the loss of his older sister. Ray’s trilogy inspired us at Healing Environments to similarly address those three stages of life, each with their unique tragedies and transformations.

In a *Child’s Book of Healing* we offer you twelve healing tools. You will note that some of them have to do with reaching out through prayer, communication and community. While some urge self-expression through creativity, poetry and ritual. Others offer resources of support through reading and websites.

But the greatest of all healing tools is love and in our small gift book we remind you—once you have been loved, you will never be alone.

Peace—





COMMUNICATION

The Four Things That Matter Most

IRA BYOCK, M.D.

Ira Byock urges all of us to say these four things to our loved ones before they die.

Please forgive me.

I forgive you.

Thank you.

I love you.

One day, I told Steven's story during a lecture at Johns Hopkins University. Afterward, a large, middle-aged black man came toward me as I was leaving the auditorium and surprised me by abruptly embracing me. At first I was taken aback. People were filing from the hall and here I was enveloped by an obviously emotional man, twice my size. He explained that he served as a chaplain at an inner-city public hospital in Baltimore and needed to tell me his story. Like many of the most affecting stories that I've heard over the years, it was about transformation at the very end of life.

A few months earlier, the chaplain had been paged to the bedside of a 33-year-old man who was dying of AIDS. Just two hours earlier the patient, Antoine, had found out that he had a teenage daughter

and that she was on her way to the hospital to see him.

"I was terrified about saying the wrong thing," said the chaplain. "I thought, 'Why me? What can I possibly do that would be of any help?' Then I remembered about saying 'the Four Things.' I was present for Antoine's and his daughter's meeting and used the Four Things to guide their visit. Antoine needed little encouragement, or help, to ask, 'Can you forgive me?' and to say, 'Thank you for coming to see me,' and 'I love you' to this frightened, anxious 15-year-old girl. And Chantelle, who really does have her father's eyes, was able to say, 'Thank you for being my father'; 'Of course, I forgive you'; and then, 'Daddy, I love you, too.'"

"They visited for just over an hour, each hungry to ask questions and tell stories. There were lots of tears; it was hard to separate the tears of sadness from those of joy. Ultimately, Antoine's fatigue and breathlessness forced their visit to end.

They kissed each other as they said good-bye."

Listening to this story, I was trembling, but the chaplain wasn't done. "I checked on Antoine later that evening and found out he had died within three hours of the visit."

This work will keep you humble.

Part of Me Died Too

VIRGINIA LYNN FRY

David sat staring at the piano keys; he just didn't have the energy to reach them. They seemed so far from his fingers. What did the music matter, anyway? He was only twelve years old and he knew his mother was dying.

Her cancer had started in her left eye and then spread to her bones. For almost a year she had been sick from the chemotherapy treatments. The strong medicine that was supposed to kill the cancer cells in her body had also killed many healthy cells. It made her dizzy and nauseous, and she threw up a lot. For the past two weeks, she hadn't come downstairs—not even to hear David play the piano, something she used to do every day despite her illness.

A month later, David's mother was so weak she could no longer talk, and this scared him. It was as though she wasn't there anymore. Yet she *was* there—her thin body was still breathing, and her hands would often flutter with movement as if a thought had run through them. She could still hear, and she was able to open and close her eyes to answer questions. One blink for “yes,” two blinks for “no,” but the sound of her voice—a sound David had known since before he was born—was missing. He knew she would soon be gone forever. He couldn't stand not being able to communicate with her while she was here with him. It was too terrifying to lose her while she was still alive.

David remembered a game he played at school called the Squeeze Game. He thought he could teach it to his mother. So he drew a “Squeeze Game Chart” and showed it to her, quietly explaining how the game was played. First, David squeezed his mother's hand four times, saying the four words “Do you love me?” Next, he told his mother to squeeze back three times for the three words, “Yes, I do.” She weakly closed her hand around his three

times. Then David squeezed twice, saying “How much?” Then together they both squeezed each other's hands tightly for a long time—to show they loved each other *that* much! He pointed to the bottom of the chart where he had written “I love you” and its symbolic code, “Eye (I) Heart (Love) Ewe (You).” She smiled, closed her eyes, and squeezed David's hand three times: “Yes, I do.”

During the next three days, David sat by his mother's bed many times, telling her about his soccer games and events at school. But sometimes a quietness would steal over him. He would get a panicky feeling that she wasn't with him anymore, that he was losing her. He'd take her hand and call to her saying, “Mom ... Mom ... it's time to play the Squeeze Game.”

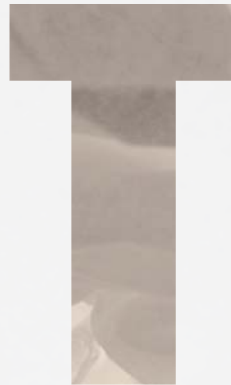
Then David knew his mother was with him, listening, even if she couldn't talk. Her gentle squeezes told him she was still there, still loving him. And she knew that he loved her. When finally she could not return his touch, David understood that she was gone forever.

When Children Grieve

JOHN W. JAMES AND

RUSSELL FRIEDMAN

*My son's father died,
and I want to know
how to help him.*



he above sentence may seem puzzling. It is an emotionally powerful statement of fact that raises many questions simultaneously.

And yet, *My son's father died, and I want to know how to help him* was the very real opening comment of a phone call Russell received at The Grief Recovery Institute. In order to understand the caller's specific circumstances, Russell had to ask the same questions that you might already be asking: Was her son's father her husband? Were they living together? Did she love the man? The caller answered yes to all three questions. As a matter of fact, this women and her husband were very much in love, and she was devastated by

his sudden death. In addition to the nine-year-old son, there were two daughters, one fourteen years old and the other five years old, about whom she was concerned.

Her husband had left the house one morning, an apparently healthy forty-year-old man. He arrived at work and suffered a massive heart attack. A chilling phone call informed her of his death.

Following his many years of experience, Russell encouraged the woman to talk about her relationship with her husband. But, with a singleness of purpose, she kept insisting that she wanted to talk only about helping her nine-year-old son. So Russell asked her to describe the problems she perceived her son to be having.

During the conversation that followed, Russell discovered that the boy was having many of the normal reactions associated with such a profound loss. But what was troubling the mom most was that her son would not talk at all about his reactions to his dad's death. She explained that when she asked him how he was feeling, he would say, "I'm fine!" and then clam up. When she asked a second time or pushed the topic, her son would retreat to his room and close the door. Russell said that he could imagine that might be pretty upsetting to her. After all, her son, whom she loved very much, had to be crushed by

the death of his dad, yet he would not talk about it. This mom was sure that whatever was going on was not healthy for her son.

At that point, Russell recalled that earlier in the conversation she had said that she loved her husband very much. He said gently, "You told me that you loved your husband very much, and obviously you have been devastated by his death." After a short pause, in a small, choked voice, she answered, "Yes." Russell pressed on, asking her another question, one to which he was sure he already knew the answer. "When you and your son are together, and you get overwhelmed with emotions related to the death of your husband, what do you do?" Immediately she responded, "I have to be strong for him; that's what everybody tells me to do. So when I feel the tears coming, I go to my room."

A very long silence followed. Russell did not interrupt. Finally and probably for the first time, she heard what she had just said. The lightbulb of awareness went off in her head. She understood. The silence ended with her saying, "Oh my gosh, he's doing what I do, isn't he?"



COMMUNITY

Community

*The Village That Emerged
to Help Raise a Child*

DAVID GONZALEZ



his is a story of hope, one born of a love that is true, deep and mad. It starts with Suzan Mikiel and Scott Kennedy, young actors who were raised in Michigan but met in New York. They married and had a child. The boy, Hazen, is this precious, impish creature known to all in the playgrounds of Hell's Kitchen.

And last year, his third, doctors found he had cancer. "The doctor said it directly," Scott recalled. "I'll never forget. He said, 'Your son has cancer.' As soon as I heard that, I thought, I'm dead. We couldn't think or do anything."

But remember, this is a story of hope, the kind we grasp onto during this, our sad season. Within hours of hearing those chilling words, the Kennedys found themselves surrounded by friends.

They were joined by a growing network of acquaintances and even total strangers who took turns cooking meals, renovating their ramshackle apartment or just watching over Hazen as he slept, to

make sure he didn't tug at the tubes that sustained him during the worst moments in the hospital.

This is a story of one boy, much love and a group of people who refused to shrink away in indifference or despair. Some of them had crossed paths and never even exchanged a nod or a word. But now they are bound by a simple vow: We can do this.

"What's really amazing is, a lot of time there is a crisis and people show up in the beginning and then they drift off," said Carey Crim, a childhood friend of Suzan's who was the first person to rush to the hospital last November. "God forbid if something happens, they show up at the end. This is a group of people who have not wavered."

The parents of Hazen's classmates at the Manhattan Plaza preschool knew that any of them could have been standing dumbstruck in the hospital. Chris and Margaret Murphy, whose son, Gearód, is Hazen's best friend, scheduled people to stay with the family every day during their vigil at Mount Sinai Hospital's pediatric intensive care unit.

The group took over a corner of the waiting room. They had a binder filled with phone numbers. Whenever Scott emerged with some technical tidbit about Hazen's neuroblastoma—a cancer affecting the nervous system—the group would dash home and do quick research on the Internet.

But just as important was the human touch. “When Hazen was intubated, we needed two people there with him,” Ms. Murphy said. “You would just sit there and rub his hair. We’d tell his parents: *It’s time for you to take a shower. Go home.*”

Carolyn Montgomery and her partner, Lea Forant, volunteered to cook meals—and not some mystery meat with cream soup concoction, but honest-to-goodness organic meals. The couple did this even though they had an infant son, and were starting a café and catering business.

Ms. Montgomery chuckles at how she first met the Kennedys; years ago when she was thinking of starting her own family, she befriended Suzan and offered to baby-sit for Hazen. Now she wants to hire him at the café when he turns 14.

“Suzan and Scott are as positive, intelligent and philosophical as two people could be,” Ms. Montgomery said. “They are not ignoring the big picture. But they are concentrating on the miracle. If it could happen to anybody, it could happen to them.”

Laura Gottlieb Feldman now coordinates the meals, which are prepared

and paid for by others. She had known the Kennedys only tangentially, through her husband’s college roommate. When Hazen took ill, she went to the hospital and kept the family company one night. They were good friends of a good friend of hers, and they needed help. She soon learned more.

“At 3 a.m., Scott comes to where I am sitting and said, ‘I know you, your son is Max, and your baby sitter would come to the playground where Hazen and I played with him,’” she said. “He told me stuff they did, like how they’d go down the slide together. I never knew this. How small a world this is, this man I never met, now I am in the hospital with him, and he knew my son.”

Hazen now is in the middle of an 18-month outpatient treatment at Memorial Sloan-Kettering Cancer Center. His hair is downy soft and wispy from the chemotherapy. His next operation is scheduled for Sept. 26. On the streets of Hell’s Kitchen, people sport baby blue plastic bracelets that read HK Strong. The letters stand for Hazen Kennedy or Hell’s Kitchen. Take your pick.

Marisa Redanty, the president of the Manhattan Plaza tenant association, the

site of Hazen's preschool, persuaded some friends to pony up the cash to make the bracelets, which are sold in places like Mr. Biggs for \$5, and can be obtained through a Web site that friends set up for Hazen: www.amazinhazen.org.

Ms. Redanty wants to see that Scott, an administrative assistant at Pfizer, and Suzan, who is still acting, find a decent place to live and has lobbied local political leaders for help. Their current apartment is clean and bright, but it was not always so. When the family was about to bring Hazen home from the hospital this year, they were terrified that his weakened immune system would not be able to survive the germ-laden, filthy hallways of their five-story 10th Avenue walkup.

That is where Lillian Colon-Jaramillo stepped in. She is a former Rockette whose daughter was in preschool with Hazen.

"I got a bunch of people together and said we had to do something," she said. "I wanted to renovate the apartment. Everybody said, 'We can't do that.' I said, 'We're going to renovate the apartment.'"

And they did: walls were painted, furniture was bought and toys were scrubbed. The outside hallways were also

cleaned. When the family finally returned home, their tiny apartment was adorable and immaculate.

If the Kennedys have a nice apartment, it is mostly because of the many friends and strangers who have come to their side. These are people who owe him nothing, who ask for nothing.

In recent weeks, hundreds of them showed up for a silent auction and cabaret at St. Malachy's Church, whose congregation has kept the family in their minds and prayers.

"When you allow people to give, you open the floodgates of love," said the Rev. Richard Baker, the church's pastor. "We have become stronger and larger because people have come together to embrace others." And the Kennedys, in return, have hugged back.

"I feel everyone is nursing him back to health," Suzan said. "He belongs to everybody and he is going to get through this. And he won't be able to do one thing wrong because everybody knows who he is."



COURAGE

Barbara's Gift

KATE STRASBURG



For you to better understand how one can be healed without being cured, I offer you the story of Barbara's death.

My dear friend Barbara died fifteen years ago after a courageous seven-year struggle with ovarian cancer. Barbara was an exceptional patient and an exceptional human being. She had much to teach us all.

I reconnected with Barbara about twenty years ago, after both she and I had moved back to the West Coast from the East. She had come out to receive medical care at Stanford Hospital; I had relocated with my husband and family. For more than five years, Barbara and I got together several times a week. Oddly, these visits always cheered me. There was no question that Barbara was helping me more than I was helping her.

Barbara's life was laced with beauty. She had a tiny garden which she transformed with loving care. We would sit out in it, and as she reveled in each flower, I, who had four acres in the country,

would envy her quarter acre. She asked me to find her a beautiful canary, to fill her house with song.

Barbara's incredible gift was her zest for life. Until the end she asked me to buy her wonderful velour warm-up suits in strong vibrant colors—teal and purple were her favorites. She asked that they be large enough for her teenage daughter, Ada, to wear when she was gone. She bought herself a beautiful handmade ring which she wore daily and planned as a gift to Had, her son. Her zippy red car was also bought with an eye to the future, as a legacy to her first sixteen-year-old.

Barbara asked each of her close friends to write a chapter of memories about her for her children. She asked me, a passionate gift buyer, to be her two children's fairy godmother. It was her way of living on in their lives, for Christmases and birthdays, in perpetuity.

Barbara's favorite holiday was Christmas. She loved it so; the tree would be up the day after Thanksgiving and stay well into the New Year. Her last year, putting up the tree was particularly poignant, as we all realized she would not live until Christmas Day. She had convinced her wonderful doctors to allow her to die at home. Ten days before she died, Barbara organized a series of daily open houses. From five to seven, old friends were invited to bring food and memories, wine and guitars, to sing songs and celebrate our lives together.

Not traditionally religious, Barbara felt a deep kinship with Native Americans. Her grandfather's farm in New Jersey had a Native American burial ground on it, and Barbara's childhood was filled with a recurrent dream of herself as a small Indian girl dressed in animal skins, running from a bear.

A week before she died I struggled to come to terms with my own grief and loss, and to help my children, who loved Barbara as well. One day I wandered into a children's bookstore and was immediately drawn to a beautiful book about an old Indian woman's death. (*Beyond the Ridge* by Paul Goble). In the story, the old woman left her weeping family behind, longing to let them know she was well and happy, and began an arduous ascent. From the top of a high ridge, she looked down at last into a beautiful flower-filled valley. There, around a group of tippis on the banks of a lovely river stood her ancestors, welcoming her with outstretched arms. The old woman began to run, as swiftly and easily as a young girl, to meet them.

I took the book to Barbara's house that day, not quite sure of what it was about. I offered it to her cautiously, saying I hoped it might be of some help. Barbara read the short book in silence, and then

hugged it to her chest joyfully. "This is exactly what I believe! I want it read cover to cover at my memorial service!"

Barbara's memorial service was a beautiful occasion. She had involved each of us in its planning. Barbara had loved show tunes, and a friend with a wonderful voice sang her favorites. Another close friend played the piano. A third was in charge of taping the service for us all. Barbara's daughter and a young friend who had also lost her mother to cancer sang a touching duet—*You Are the Wind Beneath My Wings*.

Others spoke movingly of how much Barbara had meant to all of us. We cried with pain at our loss and joy at the great gift Barbara had brought us. Barbara lives on in all of us—teaching us how to live and die.

Ten Guidelines for Living With Death

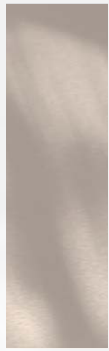
1. ACCEPT YOUR SORROW. Do not try to be brave. Take time to cry. Crying is not a sign of weakness. It is a natural expression of sorrow.
2. TALK ABOUT IT. Find a family member or friend to talk to. Your friends may act embarrassed at first. You can help them and you by talking about the death of your loved one. Find someone who has experienced a similar sorrow. Talk often.
3. KEEP BUSY. Do the usual things that keep you busy.
4. EAT WELL. Your body needs good nourishment during this time of sadness.
5. EXERCISE REGULARLY. Exercise will help you sleep better and keep your mind healthy. Do your normal exercise or start a new physical activity.
6. ACCEPT YOUR UNDERSTANDING OF THE DEATH. You have probably asked “why” over and over and have gotten no satisfying answer to your question that you feel sure about. You probably understand a little why someone died. This answer is okay for now. Some questions have no answers.
7. GIVE OF YOURSELF. Find a way to help others. Helping someone else will probably help you feel better.
8. KEEP A JOURNAL. Write or draw your own thoughts in a journal. This may help you get your feelings out.
9. FIND STRENGTH INSIDE YOURSELF. Spend some time alone bringing peaceful thoughts to your mind. If you pray, praying to God for peace may help.
10. GET HELP. If you are not able to stop feeling sad or angry, find an adult to talk to who can help you or get help for you.

MARY JANE CERA, M. ED.
FROM *Living with Death*

Grief Dreams

Susan's Dream: Jackie's Sign

T.J. WRAY



dreamed there were bees in my youngest daughter, Bethany's bedroom, causing her to scream and run away. I ran into her room and quickly swatted the bees out the window. Looking to tell her that her room was now free of bees, I went out the back door of the house in which I had grown up. My father and brother, Russ, were out in the yard. Dad was sitting on our old, red picnic table, the one he had made so many years ago. Russ was rinsing out the small colorful, fish-themed plastic wading pool my children played in when they were toddlers. Neither had seen Bethany, so I called out for her.

At that moment, I felt someone come up behind me and press against me. Then that someone wrapped their arms around me tightly

and with much care. Wondering who it might be, Jackie's face came full around to look me straight in the eye. She was smiling, and the glow that radiated about her exuded love. My spirit was immediately lifted beyond words. My Jackie was there!

She was quietly mouthing words I couldn't understand. Needing so badly to hear her message, I asked her to repeat her words, all the while knowing full well that she had passed away many years ago. Even though she repeated her message, I still could not hear. Her words were soft and muffled, so once again, I asked her to repeat what she said. At this point, she gently took my hand in hers and began doing what I suspect was sign language, in the palm of my hand. Her hands felt warm, soft, and smooth, just like they always were.

By this time, I was beginning to panic, worried I would never know her message and she would disappear. I felt such urgency to tell her, "I love you! I miss you!" Her hand grew still, she stopped signing, and then her smile grew wide. Her face came closer. So close, it touched my cheek. All the while, I could still feel the length of her body pressed against mine. Sadly, the dream slowly faded, and she was gone.

FEELINGS UPON WAKING

I awoke and found myself lying on my side with my arms wrapped around myself, sobbing. The feel of Jackie, her physical presence, was still very much with me, and I refused to move for fear that I would lose the *feel* of Jackie. I lay there, silent, eyes closed, for several minutes, reveling in the sweet caress of my lost daughter. As my tears subsided, a comfort washed over me.

THE BACK STORY

During the summer of 2000, I was beside myself with mixed, bittersweet emotions—emotions so powerful, I finally sought the help of a therapist. Therapy I so badly needed and never received after the loss of two of my four daughters.

My first loss came at the hands of the narrow-minded thinking of the 1960s when, as an unmarried pregnant, seventeen-year-old, I was forced to give up my firstborn daughter, Joanne, for adoption.

My second loss happened in 1990 with the death of my sixteen-year-old daughter, Jackie, from leukemia. I'm certain that the reason for the sudden

surge of emotions was that my third-born daughter, Kristine was getting married that week, and although I was happy and excited for her, I felt devastated that Jackie would not be there. Even though I was filled with delight because I had reconnected with my daughter Joanne in 1999 (and she was going to serve as a bridesmaid in Kristine's wedding), I worried about how I would survive the day without Jackie.

But this dream made me feel as if Jackie had entered my soul to soothe the ten-year wound that resulted from her death. And I think she wanted to remind me that she is always with me. It's been nearly four years since this particular dream occurred, and there are still times when I can actually feel her body's warmth at my back, or by my side. I can still envision her beautiful, bluish-green eyes peering into mine.

I will always cherish the love we shared.

tools for dealing with the tragedies of life as well.

When five-year-old Devon, a member of Betty Peck's kindergarten, died of Reye's syndrome, Betty used every ounce of her imagination, compassion and creativity to help Devon's small classmates deal with their loss.

"Each day we sent a large mural for her hospital room. The bed was always drawn first. Then surrounding the bed were flowers everywhere with Devon's face peeking through. The next day, it was the hospital bed with angels dancing everywhere on the bed, the walls, the ceiling with Devon peeking through. Each child made their own flowers, cut them out and pasted them on the mural, which was sent to the hospital each day.

Several days later, after the children had gone home, I was called down to the office to hear what we had all feared. When I went back to the room some parents were still there and I asked if they wanted me to tell the children that Devon had died. They all agreed it would be best if they all knew it at once and could come home and tell their parents. So after school the next day I wrote another letter to the Kindergarten parents:

[After a day of acting out Devon's ascent to heaven as an angel] . . . We hurried

back through the garden gate, filled with questions that have no answers. The afternoon children went off to have their lunch, and the morning children picked forget-me-nots to take home. Around the flowers were the paper angels holding hands carrying the message of the day: 'Devon, five-years-old forever.' I imagined Devon free to express forever the spirit of her five-year-old spontaneous, joyous Spirit of discovery.

Jenni came to have lunch with the afternoon children. As I came through the golden gate, she said, 'We found a note from Devon'. All the children came running up, telling us that Jonathan had found a message from Devon in the garden. We all gathered around as I held the pink paper kissed by the rain and the sun. Yes, it was Devon's. There was her name with her 'N' marching along in the other direction. We could see all her favorite words: 'To Mom, To Dad, Love, Devon'. This little pink paper had waited until this day to be found. And John said, 'She must have dropped it on her way.'

When the afternoon children left for home, they picked their blue forget-me-not bouquets and put their paper angels holding hands dancing around the flowers, and on each was written the message of the day: 'Devon, five-years- old forever.'

Hugs, bp"

“This is all about the F-word,” Elaine said, mid-renovation. “*Fun.*” She enlisted decorative painters Glenn and Austin Palmer-Smith to make the divider wall into a visual welcome, since it’s directly in the sight of the entryway. The father-and-son team scouted New York’s Central Park for their *Friendship Tree* mural, which has space for every child who visits to put his or her name on a paper leaf and tape it to the tree. At the mural’s base, a pile of colorful and fruit-shaped beanbag chairs encourage flopping and nestling.

A sectional sofa from Ikea and an Elaine-designed color-block mural transform the former closet into an intimate hangout nook. Masking off and painting the blocks demanded such meticulous attention, Elaine says, “It almost drove the painting team crazy.” The resulting checkerboard uses zany colors such as Purple Flurp and Rip Curl Red, and it not only disguises wall defects but also offers a view that combats the absence of windows.

The 27-year-old founder of Project Sunshine, corporate accounting executive

The best description of this Good Works Makeover challenge—turning a boxy, characterless office into a kid-friendly activity room—resides in the recipient organization’s motto. “Bringing Sunshine to a Cloudy Day” is the tagline of Project Sunshine, a volunteer-driven program that provides support to children with medical issues ranging from broken legs to terminal illness.

Project Sunshine’s new midtown Manhattan office was clouded with competing demands: It had to house both the small staff that runs the organization and a recreational space for Club Sunshine, a new program for kids with ailing family members. Club Sunshine will be a place for those kids to simply have fun—whether in arts-and-crafts projects, goofing around, or curling up with a book.

One of Project Sunshine’s staff social workers, Jessica Geller, came up with the idea for the program. Several

years ago, when her uncle was diagnosed with terminal pancreatic cancer, she saw that her two cousins, then 11 and 16, needed support, but so did the people they normally would have turned to. Everybody was stretched thin.

“Family illness brings up so many emotions for kids,” Geller explains. First, there’s the guilt. “Children, especially young ones, blame themselves and have a hard time understanding this has nothing to do with them,” she says. Routine vanishes, and kids may not know who’s picking them up from school or where they’ll be sleeping on any given night. Children may respond with anger, denial (especially if a parent’s condition is terminal), and acting out as a way to make the outside world match their internal chaos.

Chaos wasn’t what Good Works goddess Elaine Griffin saw when she toured the site; cavelike would more aptly describe the windowless, rectangular space. The designer’s first step was to have *O at Home*’s construction partner, Lowe’s, grab four more feet of room length by moving a divider wall between the activity area and the staff’s space. At the opposite end of the room, Lowe’s created a small alcove by demolishing a storage closet. These modifications gave Elaine just about 12 feet by 24 feet to work with, and the plan she came up with was to divide the space into discrete activity zones, each one more engaging and interactive than the next.



Expression

EXPRESSION

My Paper Memory Quilt

BILL ZIMMERMAN



patchwork quilt that is true to our memories and reflects the fullness of our lives should include

panels that reflect some of the heartache that each of us experiences, along with the laughter.

Think of the terrible terrorist attacks of September 11, 2001. As we all tried to come to terms with the destruction, many school children created memory patches for quilts, which helped them express and share how they felt about the tragic day. Deep feelings and emotions went into every stitch. Some of these finished quilts were hung in schools; others were presented to fire and police stations that had lost brave people.

I encourage you to work together with an older family member on a memory quilt project. It's a helpful way to get through sad or terrifying times. You see, older people have lived through times of war, of great personal loss and of national crisis, such as the Great Depression. By sharing their experiences, they show us how resilient the human spirit truly is.

Here are a few ideas for quilting squares that acknowledge the sad but important parts of our lives:

∞ A square to honor someone whom you loved and lost, such as a family member who was special to you.

∞ A patch for the tree of life, a symbol of hope.

∞ A patch forgiving someone for something hurtful they did to you.

∞ A patch for the time you were very ill, or hurt, and your friends rallied around to cheer you up and support you.

∞ A patch honoring someone who helped you get through a tough time.

∞ A patch for the time you planted flowers in memory of someone.

∞ A patch showing all the things that comfort you.

∞ A patch for all those who watch over you.

∞ A patch showing what you have learned from your grief or mistakes.

∞ A patch to celebrate the courage someone you know has shown in dealing with an illness or disability.

∞ A patch for the spiritual beliefs that help you get through hard times and help restore peace of mind.

∞ A patch for the time you helped someone in need.

∞ A patch for the lessons you have learned in overcoming a defeat or loss.

∞ A patch of thanksgiving for getting through a very difficult time.

∞ A patch showing the blessings in your life that you sometimes take for granted.

Epilogue


Living in New England, one is never far from the presence of death. The lush green countryside is dotted with centuries-old graveyards. And the family plots hold tiny tombstones, one, two, three, even four in a family, honoring the loss of beloved children at an early age.

The Boston Brahmin and poet, James Russell Lowell, lost three of his children in the mid-1800s. His touching poem, *The First Snow-Fall*, mourns the death of one of his small daughters.

As we were working on this issue, my dear friend, Marcia, brought me a treasure from her partner, Bob's, massive 18th century barn, here in New Hampshire, filled to the rafters with wonderful antique books. It is a large and elaborate tome, a touching tribute to a twelve-year-old boy, the beloved son of Elizabeth and Fredrick Bradford, who died in 1841 of an unknown illness, leaving his poor parents bereft.

To assuage their grief, Elizabeth and Fredrick created this beautiful memorial to their beloved child. They had it printed in England and illustrated by the noted painter of the day, Benjamin West. The engraving on the opposite page is part of this touching treasure.

NOTE: FREDRICK BRADFORD WAS A DIRECT DESCENDANT OF WILLIAM BRADFORD, CAPTAIN OF THE MAYFLOWER AND GOVERNOR OF THE PLYMOUTH COLONY.



*To children
who have lost loved ones,
To loved ones
who have lost children,
We send you
heartfelt comfort and love.*

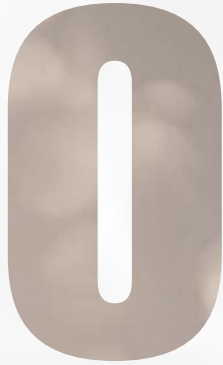


*helping
Others*

HELPING OTHERS

*A Mind of Winter: Poems
for a Snowy Season*

DONALD HALL



One of the leading members of the Boston “Brahmin caste,” James Russell Lowell (1819-1891)

was born into a distinguished Cambridge family. After making a name for himself as an undergraduate poet at Harvard, Lowell took a law degree, but his career quickly veered off toward literature after the success of his first book of poetry in 1841. A prolific and versatile writer, Lowell is best known today for two long satirical poems, both published in 1848: *The Bigelow Papers* and *A Fable for Critics*. During this period, Lowell’s life was devastated by the loss of his wife, his mother, and three of his children, one of which is the subject of “The First Snow-Fall.” Of this touching poem, Lowell wrote to his editor: “May you never have the key which shall unlock the whole meaning of the poem to you.”

The First Snow-Fall

The snow had begun in the gloaming,
And busily all the night
Had been heaping field and highway
With a silence deep and white.
Every pine and fir and hemlock
Wore ermine too dear for an earl,
And the poorest twig on the elm-tree
Was ridged inch deep with pearl.
From sheds new-roofed with Carrara
Came Chanticleer’s muffled crow,
The stiff rails softened to swan’s-down,
And still fluttered down the snow.
I stood and watched by the window
The noiseless work of the sky,
And the sudden flurries of snow-birds,
Like brown leaves whirling by.
I thought of a mound in sweet Auburn
Where a little headstone stood;
How the flakes were folding it gently,
As did robins the babes in the wood.
Up spoke our own little Mabel,
Saying, “Father, who makes it snow?”
And I told of the good All-father
Who cares for us here below.
Again I looked at the snow-fall,
And thought of the leaden sky
That arched o’er our first great sorrow,
when that mound was heaped so high.
I remembered the gradual patience
That fell from that cloud like snow,
Flake by flake, healing and hiding
The scar that renewed our woe.
And again to the child I whispered,
“The snow that busheth all,
Darling, the merciful Father
Alone can make it fall!”
Then, with eyes that saw not, I kissed her;
And she, kissing back, could not know
That my kiss was given to her sister,
Folded close under deepening snow.

JAMES RUSSELL LOWELL

Reading Materials

Another Morning: Voices of Truth and Hope from Mothers with Cancer

LINDA BLACHMAN

Armsful of Time: Psychological Aspects of Life-Threatening Illness

BARBARA SOURKES

Beyond the Ridge

PAUL GOBLE

The Creative Journal for Children

LUCIA CAPPACHIONE

The Creative Journal for Teens

LUCIA CAPPACHIONE

The Four Things that Matter Most

IRA BYOCK

Finding Your Way After Your Child Dies

PHYLLIS AND KENNETH WEZEMAN

Grief as a Family Process

ESTER SHAPIRO

Grief Dreams

T.J. WRAY

Guiding Your Child Through Grief

M. & J. EMSWILER

Helping Teens Work Through Grief

MARY KELLY PERSCHY

How to Help Children Through a Parent's Serious Illness

KATHLEEN MCCUE

If I Get to Five: What Children Have to Teach Us About Courage and Character

FRED EPSTEIN AND JOSHUA HORWITZ

Kindergarten Education

BETTY PECK

Living with Death: Activities to Help Children Cope with Difficult Situations

MARY JANE CERA

Miss Rumphius

BARBARA COONEY

Moonbeam: Meditations for Children & Starbright: Meditations for Children

MAUREEN GARTH

My Paper Memory Quilt

BILL ZIMMERMAN

Part of Me Died Too: Stories of Creative Survival among Bereaved Children and Teenagers

VIRGINIA FRY

Rituals of Healing: Using Imagery for Health and Wellness

J. ACHTERBERG, B. DOSSEY, & L. KOLKMEIER

Transcending Loss: Understanding the Lifelong Impact of Grief and How to Make It Meaningful

ASHLEY PREND

When Children Grieve

JOHN JAMES AND RUSSELL FRIEDMAN

Young People and Chronic Illness: True Stories, Help, and Hope

K. HUEGEL

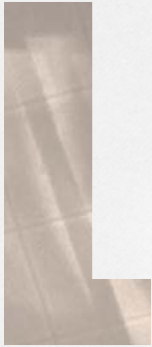
A Mind of Winter: Poems for a Snowy Season

INTRODUCTION BY DONALD HALL

Please visit www.healingenvironments.org for additional materials. Resource lists are in the "Healing Tools" section.

Roses in November

ANONYMOUS



Laurie, age 14 and my daughter Sonia's best friend, died in October, of an overwhelming allergic reaction to restaurant

food. Laurie—the charming young poet, actress, singer, dancer. She was out with us, me and my family.

We all blamed ourselves: I, for not realizing the potential severity of a peanut allergy; Sonia, for waiting too long with Laurie in the restroom before alerting adults; my husband, for not insisting on seeing a printed list of the food ingredients. He had asked the waitress. Check with the cook, he said. The cook didn't speak English, we learned later. No one there understood the urgency of the question. Five minutes after eating, Laurie's reaction started. Her EpiPen failed to release the medication. Thirty minutes later she was on life support. Three days after that, her parents gave permission

for her organs to be donated. They had Laurie's favorite saying inscribed on her headstone: "God gave us memories so we could have roses in December."

My route to work at that time took me past the cemetery, and every day I parked, walked up to Laurie's grave, and sobbed my heart out. Usually it took me the rest of the 45-minute drive to work to stop crying.

One morning—an especially cold one for November in New Jersey—I stopped as usual to offer homage at Laurie's grave. The grief, still overwhelming, welled up, and I sobbed uncontrollably as I drove away. Almost immediately, I noticed a fragrance like roses in the car. I knew no florist shop or greenhouse was on the route, a two-lane country road bordered by open, fallow winter fields and bare leafless trees. The fragrance grew stronger, and with it came a sudden sense of deep inner peace. I knew then that Laurie had come to me with roses and reassurance.

I have visited Laurie's grave many times since that day and wept some, prayed some, meditated some. But the deep, racking grief is gone—healed forever by roses in November.

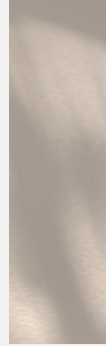
The Peace of Wild Things

When despair for the world grows in me
and I wake in the night at the least sound
in fear of what my life and my children's lives may be,
I go and lie down where the wood drake
rests his beauty on the water, and the great heron feeds.
I come into the peace of wild things
who do not tax their lives with forethought
of grief. I come into the presence of still water.
And I feel above me the day-blind stars
waiting with their light. For a time
I rest in the grace of the world, and am free.

WENDELL BERRY

*Home Away From Home
for Dying Children*

LAURA NOVAK



f the house were a hard sell, the pitch might go like this: Hamptons-style estate on five gated acres above San Francisco Bay. Classic

clapboard exterior; gabled roof with large stone chimneys. An open floor plan of 15,000 square feet. Eight-burner Wolf range. Great rooms, music, computer and TV rooms. Two guest suites, meditation sanctuary, pet kennels, rose garden and waterfall.

But the house, with its eight bedrooms and private bathrooms, has one final feature that distinguishes it from any other home: the temperature-controlled wake room for families who need several days to say goodbye to the child they have brought here to die.

When it opens its doors to the first pediatric patients and their families in March (2004), the George Mark Children's House will become the only independent site in the country to provide medical child care and end-of-life management for children.

“If we take on the medical piece as much as the family wants us to, that then frees up the family to deal with the emotional needs of each other, of the child who’s dying and of a sibling,” Dr. Beach said.

Dr. John Saroyan, a fellow in pediatric pain management and palliative care at the College of Physicians and Surgeons at Columbia University, has been studying the George Mark Children’s House since it broke ground in 1999.

“I see the opening of George Mark as a symbol that it’s time we make this part of our standard of care for pain and symptom management,” Dr. Saroyan said, “as well as psychosocial and spiritual care for children with life threatening conditions.”

Christy Torkildson, a pediatric palliative care nurse who is the house director of programs and services, said the first referrals would come from Bay Area pediatric hospitals: Children’s Hospital and Research Center at Oakland, Lucile Packard Children’s Hospital and the University of California, San Francisco, Children’s Hospital.

Children who are not expected to live beyond 19 are eligible for the house. A bed there will cost \$1,400 per day. Families will pay on a sliding scale based on their finances. Ms. Torkildson said the children’s house was hoping for Medicaid and MediCal reimbursements. At this

point, there is not even a code for such a program on any insurance plan, so the house will have to rely on raising private money. The program cost estimates, based on similar homes overseas and adjusted for labor costs in the United States, are about \$3.5 million a year.

The goal is to keep at least two bedrooms available at all times for plan-ahead respite care for families to use up to four weeks a year.

End-of-life care will always take precedence over respite care, Dr. Beach said.

And then there is the blending of these two components. Over time, families seeking respite care may bond with staff members and perhaps find a favorite bedroom. They can then choose to return to familiar surroundings when their respite needs give over to the final days of their child’s life.

“This is going to be a refuge for families who are confronting what I think is one of life’s most difficult moments,” Dr. Hull said. “And there is going to be a wonderful trained staff of people, sensitive to the needs of the family and responsive to cultural traditions. I mean, really, the safe harbor in the storm.”

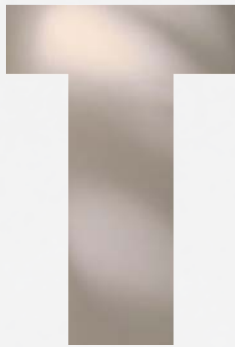
who supports herself by documenting festive family occasions—including the wedding of Microsoft chairman Bill Gates and his wife, Melinda—Johnson also makes intimate portraits of terminally ill newborns and their parents at Seattle’s Children’s Hospital and Regional Medical Center. “I photograph parents with their hands on the baby, with their wedding rings showing—the things you’d do with anybody,” says Johnson of the pictures she has taken of more than a dozen families. But hospital grief counselors say Johnson’s portraits are anything but ordinary: “Lynette helps people heal,” says Michelle Frost, nurse manager of Seattle Children’s Pediatric Palliative Care Service.

Johnson’s awareness of the pain felt by such families began in 1984, when the infant son of a close friend, Joan Reijnen, died at 3 months, after being born severely premature. Urged by friends to move on, Reijnen instead shared pictures she had taken of her baby during his last weeks of life. “In our society we don’t allow that kind of opening up,” says Johnson, the mother of two grown daughters. “We just don’t experience death in a healthy way.” Years later Johnson was asked by her sister-in-law, who had delivered a still-born daughter, if she would be willing

to photograph the child. “Taking those pictures was one of the hardest things I’ve done,” says Johnson. “But I knew if I could do it for my niece, I could do it for anybody.” She then approached the staff of Children’s Hospital with an unusual offer: “If any of your parents want photos of their baby,” she told them, “I’ll do it as a gift to them.” For parents who request Johnson’s services, her work is indeed that. “She was able to capture what we could not,” says Carin Brimley of Johnson’s pictures of her son Adam, who died at 16 weeks last August, after being born with spina bifida and heart defects. “His content face, and how he just could not be comfortable in his body, and his little crying face without a cry.” Alice and Dave Adams, now pregnant again, have asked Johnson to photograph the arrival of their new baby in March. But Josiah will always be a part of their lives. “I love showing him off,” says Alice of the portraits she has scattered around her Seattle home. “This is sort of what we have instead of him—it’s Lynette’s pictures we cherish.”

*Rituals of Healing: Using Imagery
for Health and Wellness*

JEANNE ACHTERBERG, BARBARA
DOSSEY, AND LESLIE KOLKMEIER



Time and your healing rituals will help you ease loss and grief, as V. Durling-Jones, a friend and professional, shared with us after the sudden death of her son Sean:

“There is a holy purpose in grief, and nothing should stand in its path. Grief begins with so few words. Sounds take shape traveling from a great distance. Within, a reserve is sensed. Something sacred that holds a luminous darkness that stills the mind even as the heart shudders with waves of deep sorrow.

The natural quality of grief is ancient and bone bare. It tolerates nothing false. Grief is unrestrained; conscious effort is not required.

A mother who has lost a child learns what true freedom is. It is being cut free from the knot of habit, customs, rules. It is not being bound by considerations or even fear, for the worst has happened. Your

child is dead, and you live. A mother’s lament begins.

Your heartbeat creates a tone for your body to hear. It drums and moves you slowly forward with your family even as you weep and prepare to say your last good-bye.

Now is not the time to be a bystander. It is crucial that you support and include your other children and family in the vigil, the wake, the funeral, and the burial or cremation ceremonies. They, too, are in shock and disbelief. And it doesn’t end there.

Let nothing be left undone, unsaid, unwritten or unsung in this farewell. This is not the place to lose your courage or even your humor, for you will need both of them to sustain the intense suffering you have yet to bear.

Nature provides the exact dosage for dealing with the constant strikes of pain we experience. Usually there is no real need for outside medication. Your body in its perfect wisdom gauges your requirements and numbs you accordingly. You will feel cold, but your bodymind will not allow more pain than you can tolerate. To disrupt the natural safeguards may only postpone the initial pain in your mourning process.

During the vigil and the wake your only thought is to do everything you can do to console your children and other family members. You realize they have the same concern for you. Plan the funeral

Our elders teach us that no matter how great our grief, we can—with encouragement, through grit, with time, or with hope—get through a terrible experience, learn from it, and maybe even grow a little wiser. By example they show us that everyone has strength that we can call upon when sad things happen. So, I suggest that you talk with someone older whom you love and trust about what is on your mind as you create art to express yourself for your quilt.

There is one other reason why we should devote some quilt squares to reflecting our experiences with grief: We need to remember these events and the people who are part of them. That is how we honor them. Your quilt will help you remember what is important.

Saying Goodbye Forever

FRED MOODY



A few days after his birth on Jan. 10, 2004, Josiah Bennett Adams is swaddled in a blanket at a Seattle hospital. As his mother, Alice, hovers close by, photographer Lynette Johnson snaps his portrait. “To get the best picture,” Johnson gently tells his mother, “I’ll need you to hold him.” “I can’t,” Alice Adams answers. The child was born with health problems so severe, she explains, that to even jostle him could be fatal. “He might die,” she says, and both women burst into tears.

Within a week Josiah—born with severe brain damage from oxygen deprivation during birth—left the world forever. But for his parents, whom Johnson coaxed into holding Josiah’s tiny, pink body in their arms for a series of black-and-white photos, his life will be more than a memory. A photographer



Once you have been loved, you will never be alone.

When my dear friend Talton died, I was unable to say goodbye. I wrote this letter to his six-year-old grandson, Kai. It helped both of us.

Dear Kai,

A long time ago, when your mom was a little girl. I was a good friend of Omi and Pap's. We lived in the same big city (New York) and had houses next door to each other at the beach.

I loved your Pap. If I shut my eyes I can see him now with his great big smile and his twinkling eyes. I can hear his voice, too. He had a big warm, bear hug of a voice that would wrap around you and give you a squeeze. I can also hear his laugh. It was big and warm and strong. He loved to tease and loved life a lot. The French people call that *joie de vivre* (joy of living).

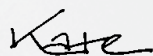
I know when he got sick he changed, the way very sick people sometimes do. That must have been hard for you. I know how much you loved him and he loved you. Grandchildren are one of life's greatest joys and you were his.

I heard that when he was very sick you sat outside his room and played your guitar for him. And you brought him your pet rat to cheer him up. I'm sure it did, even if he was too sick to tell you.

A few days after he died I went to see a friend of mine. She said, "How are you?" I said, "Fine." She said, "You don't look fine." I said, "A very dear, old friend of mine just died and I didn't get to say goodbye to him." "Say goodbye to him now," she said. And I shut my eyes and told your Pap how much I loved him and how glad I was that he had been my good friend and how sad I was that he had been so sick and then I felt better because I knew he knew.

I know you miss him very much, Kai, but remember Pap's love will always be with you.

Love,



ceremonies together. In the process, some small consolation may be experienced.

The Path of Grief leads inward when you watch and listen. Didn't you bring this spirit child into the world, flesh of your flesh? This last good-bye may enable you to complete the circle; keeping a vigil through the night allows you to be closer to your child.

The vigil with your child provides a place to begin to say good-bye, the good-bye you were both denied by sudden, unexpected death. You hear yourself talking and reassuring your son.

You must now help your child to take the first steps into the Great Mystery, by talking aloud and guiding, much as you did when he was very young. Empty your mind and your heart, and give him all your love and spiritual strength for his journey.

The week following the funeral, I moved everything from my bedroom except basic essentials. I felt driven to sleep on a mat and make a low altar which I filled with family photographs, mementos, and childhood treasures belonging to Sean and my children, family poetry, drawings,

This is my wish for you...

That the spirit of beauty may continually
hover about you and fold you close within
the tenderesses of her wings.

That each beautiful and gracious
thing in life may be unto you as a symbol
of good for your soul's delight.

That your soul may be as an alabaster
cup, filled to overflowing with the mystical
wine of beauty and love.

That happiness may put her arms around you,
and wisdom make your soul serene.

This is my wish for you.

CHARLES LIVINGSTON SNELL



Poetry

POETRY

Baby Books & Photo Albums

∞ Display a picture of your child in a private or public place in your home. Create a photo collage to hang on a wall or exhibit favorite photos in special frames.

∞ Organize or re-organize photos—especially snapshots—that may be in boxes, closets, drawers, end tables, or envelopes. Chronicle the life of your daughter or son and add captions or comments.

∞ Reflect silently, verbally, or in writing alone or with others—on the stories connected with each item in a baby book, piece in a family scrapbook, or picture in a photo album. Also select special times to look at these memories, such as on your child's birthday or during a holiday season like Christmas or Easter.

∞ Select a new format for favorite pictures. Transfer snapshots to CDs or slides to videos. Take photos to a copy center and have them printed on fabric to use as the basis of a quilt or a wall hanging. For safety reasons, consider keeping a CD or video of favorite photos in a separate location, such as in a bank vault or at the home of a relative.

∞ Share extra photos with others, including family members, friends, and people in the pictures.

Phyllis and Kenneth R. Wezeman
from *Finding Your Way After Your Child Dies*

Resources and Service Organizations

Artists Helping Children

657 Ithaca Place, Hightstown, NJ 08520

www.artistshelpingchildren.org

Seeks to enhance the quality of life for sick, abused or neglected children.

Bereavement Publishing, Inc.

P.O. Box 61, Montrose, CO 81402

(888) 604-4673 / www.bereavementmag.com

A support group in print and complete grief resource center.

Candlelighters Childhood Cancer Foundation

P.O. Box 498, Kensington, MD 20895

(202) 659-5136 / www.candlelighters.org

An organization for parents of children with cancer.

Children's Hospice International

1101 King Street, Suite 360, Alexandria, VA 22314

(800) 242-4453 / www.chionline.org

An international organization that encourages and supports hospice care of terminally ill children.

The Compassionate Friends

P.O. Box 3696, Oak Brook, IL 60522

(877) 969-0010 / www.compassionatefriends.org

National organization that assists families following the death of a child.

Elisabeth Kübler-Ross Foundation

P.O. Box 6168, Scottsdale, AZ 85261

(480) 861-7511 / www.ekrfoundation.org

An organization committed to compassionate care for those who are near the end of life and their loved ones.

George Mark Children's House

2121 George Mark Lane, San Leandro, CA 94578

(510) 346-4624 / www.georgemark.org

Offers respite support, transitional care, and end-of-life-care for children with life-limiting or life-threatening illnesses.

The International Center for Attitudinal Healing

33 Buchanan Drive, Sausalito, CA 94965

(415) 331-6161 / www.attitudinalhealing.org

A family center that has support groups for children with life-threatening illness.

The Life Institute's Conversations from the Heart

www.thelifeinstitute.org/downloads/ConversationsFromTheHeart.pdf

Resource guide for talking with children about a parent's serious illness.

Make a Wish Foundation of America

3550 N Central Ave, Suite 300, Phoenix, AZ 85012

(602) 279-9474 / www.wish.org

Grants the wishes of children with life-threatening medical conditions.

Project Sunshine

102 W 38th St, 8th Floor, New York, NY 10018

(866) 778-6744 / www.projectsunshine.org

Nonprofit organization that provides free social, educational and recreational programs to children and families affected by medical challenges.

Suite Dreams Project

400 Water Street, Suite 250, Rochester, MI 48307

248.601.0799 / www.suitedreamsproject.org

Brings comfort and joy to children affected by serious medical conditions by creating healing environments.

The Institute for Family Centered Care

7900 Wisconsin Ave, Suite 405, Bethesda, MD 20814

(301) 652-0186 / www.familycenteredcare.org

Resource for families wrestling with any type of medical or psychiatric illness in a parent.

Please visit www.healingenvironments.org for additional resources



Reading

READING

They asked Tamara, a vibrant 75-year-old spiritual teacher to serve as the officiant. She led us through visualizations and meditations of healing and love for ourselves. The exercises relaxed, grounded and cleansed us in the spirit of love and beauty and connected us in grief. Then she continued the meditation to completely focus on the child, Elliott, and to hold his loving spirit in our love and as she did this she led a group meditation of love and release. As everyone was ready to receive this child in life there also needed to be a way to collectively acknowledge his spirit in death. Tamara did this in a collective and sacred way.

Nine months later within the same year they held a baby blessing for the safe arrival of their second child, Joseph. Tamara was back—to hold the space and lead a smaller group of women in an intimate blessing. Tucker and Dave chose sacred objects that were special to them; lavender and rose petals; a glass vial with ocean water, tiny sea shells and amethyst and rose quartz crystals that fit in the palm of your hand. Following a cleansing with sage we once again traveled with Tamara on a visual journey into love—to send our welcoming messages for Joseph’s birth and arrival.

I asked Tucker recently, “Looking back on this whole experience what got you through it?”

“Spending time trying to walk through the experience carefully — not numbing out or checking out despite how dark it was. I don’t think we could have gotten through this without acknowledging what had happened. We received support from our family, friends and support counselors and we found ways to create rituals for remembrance and release.” There were always a couple of days a month that the depression would get very intense—very dark. Indeed those days always passed—I was always thankful that she had taken time on her “better days” to seek support for the times when she would really need it.

Even in the moment, as the unimaginable was happening she seemed to know that life was going to go on and that there was a very real strength in her. Tucker felt it was essential to follow through on the promise of life for Elliott—that her life would be part of his legacy. And trusting that their desire to be parents would be honored in time.

It has been exceedingly difficult to write about the loss of Elliott. I can see how grief is our companion after loss and how we need to find a way to get through the dark night one step at a time.



Ritual

what his tumor would look like under the operating microscope. I wondered if I'd be able to get it all this time. Rabbi Mychal Springer, our chaplain at the time, poked her head inside the door. "Fred, how would you feel about praying with Sam and Mindy before you go into the OR?"

If you know Mychal, you'd understand that this was strictly a rhetorical question. In my experience, clergy are like every other group of professionals; some are competent, some are expert, and some are a pain in the ass. Mychal is in a category by herself: highly gifted, and immensely soulful. She looks like a petite teenager, though she's actually in her mid-thirties, and you wouldn't think so much soul could fit inside such a small person. She's a dynamo. Some people can be described as a force of nature; Mychal is a force of God.

As our chaplain, she had one of the toughest jobs at the INN—to offer people hope when hope feels out of reach, to help show them the way back to what they believe in when they're lost in grief or panic. Mychal has an uncanny instinct for speaking to children and adults in their own spiritual idiom, whatever their faith. Praying with Mychal is always an adventure. She jumps right in and addresses God as if He were standing there beside you, or perhaps just behind the drawn curtain in the ICU. Her prayers are never scripted, always spontaneous

Joseph Weilgus, broke into a broad smile when he first saw the completed makeover. “How could you not?” he asked. “I expected a cool, amazing room. I didn’t expect it to be so inspiring.” Weilgus knows from inspiring. What started as periodic visits to hospitals during his college days—the children of some family friends were ill—expanded as he started wearing clown gear to entertain children he didn’t know. Weilgus enlisted the help of friends when he saw that a kid who’d had chemo all day and was going to be up all night might like company, another kid might want to be read to, while another might need help with school work. He wanted to help them all.

“It’s ironic,” Weilgus says, “but this work makes you happy. Yes, we visit pediatric wards where kids are suffering. Sometimes we cry with them, but we’re always there holding their hands.” College campuses and corporations across the country have started Project Sunshine chapters, and individual kids run book drives and bring in their families to put together journal-making kits for hospitalized children. “We help kids who are

sick and whose parents are sick, but almost as important is getting people to volunteer, because that’s what we’re put on this earth for.”

Apparently, Elaine was put on this earth to translate human relationships and emotions into three dimensions and a unified color palette. The Club Sunshine headquarters she’s concocted overflows with “F” possibilities. In fact, she herself can’t quite settle on which aspect of this project most completely delights her: It could be the four tickets to a Yankees baseball game, donated by shortstop Derek Jeter’s Turn 2 Foundation (turn2foundation.org), for a to-be-determined child; it could be the “fish family,” four squishable and cheery felt pillows that swim along the sectional couch; or it could be watching the first group of kids enter the completed room, particularly the boy who crosses the threshold, immediately throws himself onto a beanbag chair, kicks his feet up in the air, and dissolves into giggles.

“Mission accomplished,” Elaine declares, eyeing the giggler.

“For Americans, death is a taboo,” said Dr. Kathy Hull, a psychologist in pediatric oncology who helped start the home named for her brothers. One died at 16 in a car accident; the other died at 30 from cancer. “I think we’re the only society in the world where everybody thinks they’re getting out alive somehow. And for children, it’s much worse, and not because it doesn’t happen but because it’s a topic people are not comfortable with.”

The George Mark Children’s House was created to provide the missing link in two critical components of caring for children with life-threatening illnesses.

The first is hospice care, which focuses on pain management for dying children as well as guidance and bereavement care for their families. Currently in the United States there are two options for families in these situations: children can die at home with hospice services, which are not always readily available, or they can die in the hospital. Though some hospitals have tried models similar to those of birthing units, with nicer wallpaper and furniture, some families still cannot escape the feeling of a hospital setting.

“It’s still this family coming to the place where their child has received treatment, where they have all these memories of what has gone on previously,” said Dr. Barbara Beach, a pediatric oncologist, co-founder and medical director of the George Mark

Children’s House. “And many families don’t want their child to die at home. They feel that they will forever have difficulty being in that space wherever the room is where the child died.”

The second goal for Dr. Hull and Dr. Beach was to offer a form of respite care for families. With a full-time staff, the house will serve as the middle point between home and hospital for children whose families may not have had a break in months or years.

“Because in some cases it does not exist, families cannot get respite at home and are on occasion forced to admit their child to the hospital, even though it is not absolutely medically necessary, because they have no one else to care for their child,” Dr. Beach said.

Dr. Barbara Sourkes, director of the pediatric palliative care program at Lucile Packard Children’s Hospital at Stanford University, says the George Mark house will address America’s “invisible families.”

“These are families who have a child with a neurodegenerative disease from birth and who live well into their teens,” Dr. Sourkes said. “They need total physical care. And many families are dealing with years and years and years with no break at home.”

If one of the goals for the house was to offer a middle ground for the patients, it was equally important for Dr. Hull and Dr. Beach to put boundaries around illness and death for the siblings.



Design

DESIGN

*Death in the
Kindergarten*

REVIEW BY
KATE STRASBURG



first heard of Betty Peck
from my dear friend Helene
who was ecstatic to have
discovered her kindergarten
class in Saratoga, California—

where the magic of childhood was
celebrated and children's hearts were
opened to the miracles of the universe.

I began to understand Betty's radiant
gift for the appreciation of life when she
told me of her depression-era childhood.
When forced to move back on to the
family farm for lack of work, her mother
encouraged the children to sleep on hay
wagons out under the stars in order
to enjoy the priceless gifts of the cosmos.

For over 50 years, Betty has opened
children's hearts to the wonder, to the
mystery, to the magic of this world.
And as she shares with us in her book,
Kindergarten Education, in so doing she
has given children invaluable gifts and



Prayer

PRAYER

vigil candles, prayer fans, fresh flowers, and ceremonial sage.

Prayers became conversations and chants and death songs for the son who had no time to create them for himself. Forty-nine days of talking-prayer asking the angelic beings to guide my son on his journey.

Each member of the immediate family scattered Sean's ashes in places special to him. A spirit bundle was placed and kept before the altar for him.

Always the moving between worlds; letting go of the loneliness through weeping, sound and moving prayer to returning to repose, listening, and sitting. A year goes by.

You find it difficult to speak. Your breathing habits are changing. You become aware of differences in your breath. You sense your heart breathing, your brain breathing. You notice that when you breath out, you see thought. Some days you don't remember breathing at all.

You keep a journal as an ongoing discussion with your child, seeking solace. You somehow deal with daily life, guilt,

illness, helplessness, and the grief of your other children.

Four more years go by; four years of dreams, voices, and mourning. I begin to understand the innate usefulness of creative work and humor as an antidote to loneliness and pain. My children need me and continually pull me onto the more solid ground where they stand.

Dream walks, drumming, chanting, and round dancing lead me to my tribal traditions.

My children personify the creative weaving of compassion, intelligence and courage, and remind me of how precious each individual life is and the miracle of being together with Sean and with each other in this life and in this time and in this place.

My son Sean has taught me that the true object of death is life. I have learned that a dream can be shaped by the dreamer; that in the act of sacrifice, the sacred is manifested through surrender of all that is."

heal us—because they all open our hearts. All emotions, including anger, are sacred. “Anger is part of every relationship, including with God,” says Mychal. “But people are afraid of getting angry and alienating God when they need God most. ‘I’m angry *and* I love you’ is the toughest statement for most people, whoever they’re speaking to.”

After we finished praying, Sam invited Mychal to Mikey’s bar mitzvah, which was still nine years off. Then I went downstairs to the OR and took out Mikey’s “stupid” tumor—and prayed to God that it wouldn’t come back.

I can’t say if my hands were guided that day. But I do know that I felt Mikey’s parents beside me in the OR, and I felt the force of their love for their son. Praying with them made the OR a sacred space for me that morning. And as their son’s surgeon, that made me feel more powerful.

Today, six years later, Mikey’s a rambunctious ten-year-old boy. He went to sleep-away camp for the first time this summer. Last month he was back at the hospital for an MRI—his eighth clean scan in a row—and afterward he played a raucous game of stickball in the hallway with Jeff Allen, our senior neurooncologist.

I don’t believe God cured Mikey of his cancer—any more than I believe God made him sick in the first place. I

believe Mikey’s alive today because he’s got a loving family and a committed and talented medical team who refused to give up on him, who pooled their God-given talents to defeat one stupid tumor and save one sweet soul from a disease that most doctors will tell you is incurable.

Hope and faith play a huge part in every patient’s recover—and in the survival of every patient’s family. A parent of one of my patients asked their previous surgeon if there was any hope for her son, to which the surgeon replied, “It’s not my job to offer hope.” I emphatically argue the inverse: It’s not a doctor’s job to deprive a patient or a family of hope. None of us is God; none of us knows who will live and who will die.

Every tumor is different, and every child is unique. I’ve never felt I could say, “I’m sure” about any patient’s prognosis. I’ve seen kids die who should have been cured. And I’ve had other patients who, by all the laws of medicine should have died a decade ago who are playing professional sports today. Some people call them miracles. Others see them as statistical anomalies. From my point of view, the odds of a child’s survival are meaningless in any particular case. What often makes the difference for patients and their families is how long they can cling to a lifeline of hope during a storm that often seems interminable.

expressions of hope and humility. Since coming on board as our founding chaplain, Mychal had become *my* rabbi too.

So when she appeared in my office to invite me to pray with Mikey's parents, I didn't think twice about it. I'd never actually prayed right before surgery—certainly not with the family of the patient. But standing there in front of the light box, staring glumly at pictures of a tumor that had already resisted surgery and chemo, I welcomed her offer.

Dressed in my scrubs and operating clogs, I followed Mychal down the hall to the intensive care unit. Mikey was already in the OR being prepped for surgery. Sam and Mindy were standing beside an empty bed in the ICU where we'd be bringing Mikey in a few hours. They looked like they hadn't slept much the night before. Mychal pulled the curtain closed around us, shutting out the monitors and IV poles for a moment. The four of us held hands around the empty bed. Holding hands helps, whether you're six or sixty. I've always found that making physical contact with patients and their families is the best way to dispel the loneliness that infects the fear we're all feeling. I'm a toucher. I feel better when I'm touching someone, so I figure they must feel better too.

So we held hands while Mychal led us in prayer. That morning Mychal prayed in Hebrew and in English for Mikey's recovery. She asked God to watch over

the bed we stood around, and she asked Him to watch over the operating table downstairs. Finally, she prayed, "And please, God, guide Fred's hands so he can once and for all get rid of that stupid tumor in Mikey's head."

Sam is ordinarily a buttoned-up guy, a hard-nosed corporate attorney in his day job. But being the father of a sick son wasn't his day job. "If I was ever going to pray," Sam says now, "this was the time. As I prayed I could feel the warm tears running down my face. They weren't tears of sadness or despair. They were tears of hope. As strange as it sounds, all my anger from the day before dissolved into gratitude. I was grateful that we had some treatment options left to feel hopeful about. I was grateful that we could hold each other's hands and pray together."

Mychal thinks of prayer simply as opening your heart and giving it a voice. "Whenever you open your heart," she says, "things can happen that are beyond our understanding." What happened that morning was that by holding hands and opening our hearts, we were able to transform a moment of anger and fear into a moment of hope.

Keeping our hearts open in the midst of despair is what prayer's all about. Children evoke our greatest love and our greatest fear. When our feelings become overwhelming, we tend to shut them off. Mychal will tell you that all emotions can

vigil candles, prayer fans, fresh flowers, and ceremonial sage.

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Creativity

CREATIVITY

*The Alchemy of Love:
Transforming Loss*

KATE STRASBURG



What can be
done with
unbearable
loss?
How can

unspeakable pain be transformed with courage and vision, into an exquisite gift to the world?

We recently read of a woman who had lost her two children to a rare degenerative nerve disorder. Her response was to create a website for children with serious illness—BraveKids.org—as well as support their grieving parents.

On a recent trip to Denver to explore educational options for my teenage son, I met an extraordinary young man, Daniel Conroy. With his intense warmth and infectious good humor, I liked him immediately. But ours was to be a stronger and deeper connection. When he asked me what our nonprofit did, a strange thing happened. I answered with

words I have never used before or since: “We help people die.”

Immediately Daniel’s demeanor changed. In a hushed and reverent voice he shared his story with me: “We lost our first baby. It was absolutely horrible. She lived sixteen days. We watched her go from the most beautiful baby in the world to a shriveled and lifeless form. Seeing the life literally drain out of her. For sixteen days, we held her and tried to comfort her in the most cold and impersonal surroundings. I hated the hospital! How could my beautiful baby die in such an ugly place! I even brought pieces of beautiful silk in to transform and dignify her environment.”

Overcome with grief, Daniel and his wife, Mae, started a foundation in memory of their daughter Mclaine. Joining forces with Children’s Hospital and Centura Home Care and Hospice, they helped found The Butterfly Program—a beautiful gift to dying children and their parents. The Butterfly Program’s mission is to create healing environments for those who must suffer the pain of such excruciating loss—and to transform that loss into a healing transition—for parents and their children. Daniel and Mae want no other parents to suffer as they suffered.



SUPPORT

*If I Get to Five:
What Children Can
Teach Us About
Courage and Character.*

FRED EPSTEIN M.D.
AND JOSHUA HORWITZ



was in the middle of a tennis game when my cell phone rang. It was Tania Maher, my triage nurse at the INN.

“Fred, you have to get back up here. Mikey’s had a recurrence.” I flew up that afternoon and went straight to the hospital. It was almost midnight when I found Sam and Mindy standing over Mikey’s bed, watching him sleep. I hugged them and urged them not to lose hope. I assured them we still had lots of treatment options left.

“When I saw Mikey’s MRIs this afternoon,” said Sam, “I was so filled with rage that I cursed out loud. I kept shouting, ‘God damn it! God damn it!’ The question I keep asking myself is, Why would God let this happen again? How could He put Mikey and us through this misery all over again?”

The Schwartzes weren’t a religious or

observant family, but over the years I’ve found that there are no atheists in the OR. It doesn’t matter whether you’re secular or religious, Jewish or Christian, Hindu or Moslem. When your child gets seriously sick, you find yourself plunged into a passionate dialogue with God. Anger is as good an icebreaker as any.

I’ve also found that when you’re filled with anger and fear, it helps to be able to believe. It doesn’t matter what you believe in—I’ve seen kids sustained through terrible ordeals by their belief in Tinkerbell—as long as you believe in *something*. Even if it’s just a God to curse and berate. If you don’t believe in anything, you’re sunk.

I know from working with families of every religious background that those with some kind of spiritual framework for their crises do much better. Not that faith comes easily in the face of a child’s life-threatening illness. But it definitely helps to have a larger spiritual context for a child’s suffering, and the pain it makes a family endure. The parents with more flexible theologies seem to do better than those with more rigid models. If they can’t conceive of a just world where bad things *do* happen to good people, their anger at God can blot out every other emotion.

I was awash in my own mix of emotions the next morning as I paced in my office, preparing to operate on Mikey. His latest MRI was clipped to the light box in my office, and I was trying to visualize

Journeys in the Sand

One of the most popular rooms in Healing Environments is our sandtray room. Sandtray technique, or sandplay as it is sometimes called, is often used by Jungian analysts or children's therapists as a tool for directly accessing the subconscious. Offering a "map" of a person's central issues, sandtray can be effectively used to reveal hidden conflicts or to work through painful emotions.

Commonweal, a small nonprofit on the Northern California coast which works with cancer patients, has found that sandtray helps patients come to terms with their illness. At Healing Environments we have found it to have universal appeal, and we believe it can be modified to benefit us all.

Our sandtray room is lined with shelves of small, evocative objects—a bottle of sand labeled "extra time," a small building on fire, a bucket of miniature money. Our sandtray, a handhewn, round antique cheesemaking tray filled with concentric circles of sand, sits on a coffee table in front of a loveseat. Visitors are invited to select those objects to which they are drawn for some mysterious reason. They are asked to "turn off their brains," to operate intuitively, rather than analytically. The objects are placed in the sand again without conscious thought. Once the sandtray is complete, its creator is invited to step back and survey the miniature scene. Does it tell a story? Would he or she care to share it with us or perhaps reflect upon it silently? The results are often dramatic.

KATE STRASBURG

A Light in the Mist, SYMBOL ISSUE, 2001

Visit our website www.healingenvironments.org for more information and a paper sandtray that can be downloaded. See the Symbol Issue, 2001.

*Love is
stronger than
everything...
stronger even
than death.*

