

The Death of a Child: Leukemia

Introduction

This account is about the life-threatening illness and then the death from that illness of a child, my child. Certain aspects of this narrative have been modified to protect privacy.

This report is taken from notes from symposia and lectures I have delivered over the years

In writing this, I am wearing two hats, really--as a psychiatrist, but also and more importantly, as a mother. I am, in a sense, writing on behalf of my daughter, whom I will call K. She died just 12 days after her 6th birthday, now 20 years ago. She wanted all people involved with sick children to understand and even to learn from her experience. She stated this hope quite directly. This is how she could help sick children since she could not get to grow up to be the leukemia doctor she had aimed to be. I carry on for her since she cannot.

I will take you on the journey of K's illness and death that filled the last 2 years of her life. Already, I am asking of you to bear witness to that which is unbearable to all of us—intense suffering and profound loss. To me, that is the mandate of any health care provider and a mandate that challenges all of us to our core. I want you to understand what we had been shaped by when we first faced K's being terminally ill. There is no experience in life more intimate or personal.

I am an adult and child psychiatrist and an adult analyst on the faculty of an internationally recognized medical center. I have been married now for nearly thirty-two years to my husband C who is also a psychiatrist and analyst at this same medical center. We have a daughter G who is now 28--she was 7-years-old at the time of K's diagnosis and 9-years-old when K died. We have a son T who is 18-years-old, obviously conceived and born after K died. K would have been 25-years-old at this writing. At the time that K got sick, we led the typical busy lives of families with two working parents.

Evaluation, Diagnosis, Early Treatment—and Complications

K's first symptom was a pain in her "tussy" that developed the night before her 4th birthday party. It was 12 days later--on Halloween actually--that she was admitted to a major teaching hospital unaffiliated with the medical center where my husband and I had appointments. K was diagnosed with Acute Lymphoblastic Leukemia (ALL). We felt lucky-- she began treatment strong and had all the indicators that predicted a highly-likely (90%) cure. From that very first day, C and I rearranged our lives. We eliminated all of our teaching and writing and speaking in order to have one of us available to K and to G always. For us, that was the only way to do it.

That month in the hospital went without many complications except for a gram-negative pneumonia and K went into remission right on schedule. That was perhaps the last uncomplicated thing her disease did.

After a few brief weeks on chemotherapy back at home, K spent the next several months in the hospital with repeated episodes of fungal sepsis and life-threatening hemorrhagic pancreatitis caused by her chemo. It was a blur of ICU crises: pain, enumerable biopsies and scans and huge IV access problems. This was our real induction into the world of her pain, disability, weakness and social isolation--into the daily uncertainty of her survival. For 50 days, she was too ill to receive any chemo. We had 5 months of outpatient chemo after which she seemed stable only by comparison. We were always still living with her illness, revolving our lives around it yet trying to normalize our time, finding fun amidst the daily medicines, dressing changes, hair loss, belly pain, fatigue and her inability to go back to school. It was during this time that K, then four-and-a-half, first brought up that she thought about dying. One night, G came downstairs from their room saying that K needed me. I found her quietly crying in her bed, distraught but not seeming in physical distress. With relief about that at least, I lay down next to her and hugged her as she began saying that she had been thinking about death. She did not want to die, she said, because she did not want to be apart from us. Not ever! I told her that we would never leave her, that we were fighting this big sickness together with all the good powerful medicines. I was emphatically hopeful with her that she would grow up big and strong, because it was still possible.

And then K relapsed. She was on chemo and after only 8 months of remission. She sensed it as we all did, even before it was discovered on a bone marrow biopsy that was routine for her chemo protocol. She always called those bone marrow biopsies her "bow and arrow" test, which seemed a fitting misnomer. Her subsequent hospitalizations for treatment of that relapse with high-dose chemo re-induction coincided with the death of my father--her beloved grandpa. He had spent the previous 4 months in the cardiac ICU without the benefit of hospice. Later, I would realize how unfortunate it was that he did not have that benefit. I have seen all too closely as a mother and as a daughter what a huge difference hospice can make.

A Turn for the Worse -- Hope Sustained

Now, for K all the odds had changed. C and I scrambled to learn as much as we could, as fast as we could. We spoke to experts across the country, weighing our options with intense care. Our best hope was a bone marrow donor transplant. Given K's multiple chemo-induced organ complications, we switched to a medical center more firmly established for its research and treatment of childhood cancer. This meant a new place and many unfamiliar people at an especially vulnerable time. After exhaustive testing of relatives near and far, we could find no related-donor match. We waited for what turned out to be four months for a donor from the National Registry. During that time, K did go back into remission but spent most of her time in the hospital with severe abdominal pain from pancreatic pseudocysts as well as sepsis and

endocarditis. Finally, at 5 years and 2 months old, K was stable enough and we had a 4/6 matched donor, our best hope. We proceeded.

K spent the next 3 months in the high-risk bone marrow transplant center of the new cancer center. She was in a sterile isolation cubicle and could not have skin-to-skin contact with anyone.

During the pre-admission discussion with the team, K asked, "Will I be able to lick mommy?" She was crestfallen to find out that she could not. C and I took turns sleeping at the hospital while the other stayed at home with G. At the hospital, we were now in a HEPA-filtered cubicle. After a full surgical scrub in order not to contaminate her environment, we slept in full surgical garb, including mask, cap, gown, booties, and double gloves. Each time we went out to use a bathroom or get something we needed, we rescrubbed and regowned.

We strategized what K might want or need days in advance because all clothing or markers or Legos had to be sterilized for three days before entering the room and, then, resterilized every two days. I can still hear the staff's repeated dictum, "on the floor out the door." K knew if anything touched the floor, it was gone for several days.

Here is one of the many points when an astute and compassionate medical care made a huge difference in K's, and our, physical and emotional welfare. K's transplant doctor, whom I will call Dr. N, set a precedent by petitioning the tumor board to allow us to sleep in that cubicle every night. Parents had previously only been allowed to visit between noon and 8pm. After that petition, overnight stay became the routine for all parents.

K's transplant did engraft and once again we gratefully returned home though life for K was severely limited life. She had severe graft-vs-host disease and required forty medicines and catheter line changes each day as well as UV light treatments three-times-weekly. She developed diabetes and briefly seizures solely from her medications. We were in the hospital more than at home during the ensuing 6 months. K coined the term, "housepital," to articulate how that felt to her. It was harder and harder to have anything like normal life as the consequences of K's illness and its increasingly debilitating treatments. We still enjoyed much however. K loved words and books. Reading to her became a survival technique. We sat by her reading through many CAT scans and procedures, as well as pain and fevers. When K was up to it we built Lego castles and played one of her favorite games called Pretty Pretty Princess. G came to visit the 'housepital' each weekend and the girls spoke on the phone each night--no matter how ill K felt--at least to say good night.

G wrote K letters sometimes giving her math problems to do like her own homework. When we were able to be together, we maintained life's routines--teeth to be brushed, baths to be taken. We broke some rules too to maximize family time. We lived with knowing that the war was far from over but we were going for cure--because it was still possible.

Throughout those 20 months before K was terminally ill, we put a lot of thought into how we dealt with K about her illness. We understood that K was bright, intuitively perceptive and

articulate. Since her early days, she had been remarkably able to name feelings in herself and others and to face the world openly. She had always been a need-to-know kind of person. She strove to convey her experience quite precisely to people. She would describe a particular pain using up to 10 adjectives. Yet she was also a person who cherished control of her privacy. We worked to preserve that amidst the many intrusions and indignities of her being a patient. K was a determined and sometimes a quite stubborn fighter, wanting control of her life and decision-making power. We looked for ways to give her reasonable control whenever feasible and actually had few struggles over her many medicines, painful dressing bandages, blood tests, insulin shots, her many food and activity restrictions. K just got it-- she knew it was essential or we wouldn't be asking her to do it. She saw herself as active on her own behalf, fighting those sick white blood cells.

We were blessed with family and many dear friends who became lifelines for each of us. However, there was little formal support. I believe that the social work and psychological staff at the hospitals wanted to be helpful but had limited time and underappreciated our need. We were, after all, an intact family, clearly loving, still functioning, able to speak up and ask questions. We were also overwhelmed, terrified, and exhausted. That we were both physicians was an asset and a liability. We were informed consumers and not intimidated by medical authority. As you might have guessed by now, K was a vocal advocate for herself, too. On the other hand, we were suffering every parents' worst nightmare. Some doctors were uncomfortable with how much they identified with us and were scared to get close to us. We were parents with a severely-ill child, struggling with our agony for her. In the face of this lack of professional support within the hospital system, we pieced together our own network. We sought out other families in similar situations. The hospital team did help with arrangements for IV medication at home. We found counselling independently for ourselves. This was tremendously helpful in sorting out our feelings and how to help G and K cope. While this network functioned well in some ways, there was no sense of cohesion, no one person or even organization overseeing her care, no one coordinating all the different teams of doctors and nurses from each of the many subspecialties now involved in her treatment. That was up to us and it was a daunting challenge.

Six months after her transplant, K relapsed again. Again. we knew it before it was confirmed by medical testing. K began having more pain in her head, her shoulder, her hip--and something in the quality of that pain and a certain gray look around her eyes told me that the leukemia was back.

Terminal Phase

K was admitted to the hospital for control of her pain and a work-up to illuminate its causes. Her MRI showed widespread holes in her bones as assessed via that "bow and arrow test." On one Friday afternoon, Dr. N, came in, said a friendly hello to K and asked C and me to step out of the room. As soon as the room door closed behind us, she said quietly, "The leukemia is back." She had clearly known for hours and arranged a room and time for us to talk. For the next two hours,

she sat with us as we sobbed and asked questions. Our immediate concern was clarifying her definitive statement: they had nothing else to offer K for cure. She would die anytime within two weeks to a year. We explored chemo and any other treatment possibilities. We emphasized our wish to get home to be all together as soon as possible. We spoke about how to talk with G and K. Dr. N did mention that there was a team that dealt with terminal care, but it was Friday afternoon and the team would not be available until the next week. She did not use the term, "hospice." K's oncologist, whom I will call Dr. S., was away but the Dr. N had spoken with him and arranged for us to also speak with him over the weekend. She even offered to come in herself. She wanted to be available to answer any questions K might have. In other words, she did absolutely all that could be done for us with the exception of the hospice piece. Dazed and overcome though I was, I felt her enormous compassion. She showed us her own angst about K. This helped me feel that K mattered to her as well. Because we had had a good relationship with her from the beginning, I felt that she was the right person to tell us. She had often impressed me with her clinical acumen and always strove to understand who K was. Indeed, as we now learned, it was she who petitioned the tumor board for one of us to be able always to sleep in K's cubicle. She argued that K would do better in all ways if we did. She maintained her capacity to guide us even while showing us her distress.

To me, that is truly physicianly. Now, however, K was no longer considered a transplant patient. At this crucial time in her life, K was shifted back to her oncologist Dr. S. who had known us but who had not been any part of K's care for a year. Because we respected her and because she was willing and cared, we kept in contact with the Dr. N for the rest of K's days -- and have ever since. We still exchange notes once a year or so. Dr. S. was caring and diligent, too, and clearly smart. But he did not try to understand K as well as the Dr. N and was acutely uncomfortable with facing K's being terminally ill. For our child, this was grievous.

That same Friday afternoon, after we had exhausted our questions, Dr. N went back into K's room and told her, with us there, that the leukemia was back. K listened somberly but did not ask for a lot of elaboration, not until she and I were alone together later that night. As we were preparing for bedtime, she began to ask her questions. First, "Will I always have leukemia?" Then, "Will I die from my leukemia?" "Will I die soon?" "Will I get to be a teenager?" Often, even before I attempted to answer, it was clear to me that she already sensed the answers. I told her that I would do everything we could, that we wanted to help her to live as long as possible, to get rid of those sick white blood cells again. And standing, leaning her head on my shoulder, as I knelt in front of her, K said, "Mommy, I would do anything to live. I want to grow up. I want to be a mommy, but I know it. I know that I won't get to grow up. I am not going to get to have my babies. I won't get to have my cow." (Remarkably, K wanted a cow--in our city apartment!). "I won't get to be a leukemia doctor." And right then and there, she immediately began to detail for me how she wanted to die: "I want to die on your lap Mommy. I want to have my lullaby tape on-- I was born to listen to that music and I want to die to it. I want you to die with me. No, no, I want you to die right after me so you can be with me when I die."

And then she asked, "How will I know when I'm just about to die?" I promised her that I would be with her no matter what. We arranged for her to ask her questions to her doctors over the

weekend and any time after that. Later, K queried one physician who appeared altogether at ease in the face of K's awareness that she was dying. When K said to this physician, "I am afraid of dying," she answered that, yes, that was like when her own children were afraid of thunder and cuddled on the bed together. To me, that showed appalling insensitivity.

When we met with Dr. S., he tried to be vague with K. As she asked him pointed questions, narrowing her window of remaining life to a smaller and smaller future: "Will I get to be 7?" "Will I make it to my 6th birthday" (-3 months away), he visibly squirmed and kept telling her that he did not have a crystal ball. He did however tell her that she was stable now, that we would know when the dying was soon. When it was soon, he would be sure to tell her. Only after we called him aside and urged him to be honest with her since she already knew did he finally acknowledge to her that she would not live to be 7 and that he hoped that she would live to be 6. For our child, stark and unbuffered though that conversation was, it was actually reassuring. She knew the truth, knew we knew it and needed to know we could all know it together. After that talk, K got less afraid. However, grievously, he neglected to live up to his promise. When she began to visibly deteriorate and saw him in clinic right before her death, he said nothing. On her final night, when we all acknowledged together that she would die soon, even though his promise had not been mentioned in the intervening three months, K queried, "Why didn't Dr S tell me?"

Let me get back to those early days of living with terminal illness. Once again we scrambled as fast as we could to find out all there was, to uncover whatever options existed in the country, in the world. It became quickly clear that prolonging life was a matter of months at best. We felt absolutely clear that, with whatever time K had left, we wanted her to be able to be at home with us as much as possible. We felt absolutely clear that K should be as comfortable as we could make her. We were determined to never leave K emotionally alone with anything she had to face. We knew that K would want to fight for as long as possible. K found meaning in life---in profound ways I believe--accelerated by living on the edge of her short span. The year before she died, when asked by an adult friend of ours whether she should get her son an iguana even though they have to be given away after a short time of growth, K told her--in her emphatic style--"Yes, I think you should get him the iguana. It is worth enjoying it for as long as you can, even knowing that you will have to say goodbye to it soon." So, we were prepared to fight at her side, to value and enjoy whatever we had left together. We desperately needed people with heart, smarts, experience and dedication to face the unbearable with us. I did not know it at the time but I was describing hospice.

When she entered the terminal phase of her illness, we were discharged home on an IV morphine pump. All of her medical follow-up remained at the cancer center. We did all IV medications at home. Her medicines were pared down to just the most essential 15 pills. We agreed on palliative chemo to give her as much comfort and life as possible. K wanted this chemo even knowing it would put her at risk for infections requiring hospitalization and made her lose whatever sparse hair had begun to grow back. In that same conversation with Dr. S., she had pointedly stated this to him in just this way. "I want to do everything there is to live as long as possible even if it

means being in the hospital.” Then, with her stance articulated, she, in a polite tone, said to him, “Do you get it?” When he said yes, she said, “Then please repeat it back to me.”

K yearned most of all to go back to school. Though that was not feasible--she was so bloated she could barely walk, so sedated by her morphine. We did arrange for a home teacher.

Hospice

Finally, I got the phone number for hospice from the hospital social worker. I remember that first conversation with our hospice team leader so vividly. She elicited our story from me with all the facts but also tried immediately to understand who we were facing our daughter's death. I got off the phone and felt for the very first time since K's diagnosis that we had a net to catch us, a knowledgeable unflinching and overseeing presence to guide us. The team devoted itself to figuring out what our needs were, what needs of ours were not being met even if we didn't know to ask. They strove to work with what K wanted in her dying. They took in the whole picture--from medical to emotional to spiritual--and devised a plan. The team leader would talk with C and me weekly. She also came to our home to meet K and G. A counsellor was assigned to work with G and with K. Because she was getting to know K, she also would be able to continue with G after K died. A nurse was to visit weekly, more if our needs changed. Astonishingly, the team recognized the importance of my mother-in-law and arranged to be available to her as well. They could have offered us medical care and equipment. But K had always been clear that she wished me to do all of her IV changes, dressings, injections and medicines even if they were “hurty.” Wrenching though this always was for me, I was determined to continue to do it for as long as she wanted. We were also lucky that K's pain doctor from the cancer center worked with us on the hospice model. This doctor was remarkably compassionate, unafraid to talk with K about her pain and her dying, and saw her mandate as caring for the complete person that she was. This was K, a person, who happened to be dying. She saw K as having life to live as she wanted for as long as possible. With her, too, we still maintain contact..

Over the next 3 months, K remained on her chemo and did have a few weeks of easing of pain, more alertness and greater mobility. C and I stopped working completely. We tried to do some of K's favorite things. One of my most cherished memories from that time is of K on the bicycle bought for her 5th birthday but that she was never well enough to ride. She rode it at the playground, drawing gaping stares from people as I ran behind trying to keep up holding the IV bag connected to her chest by her IV tubing. She pedaled with such exuberance and joy merely at her capacity to do it. Food and activity restrictions were no longer useful so we cooked some of her favorite foods, went to the movies and to a ceramics studio that she loved. K was determined to learn to read before she died. She worked diligently at her letters. At times, K was so sedated it seemed that she was already gone. She had a reversed sleep-wake cycle, often sleeping stuporously until midafternoon and then up all night. At times she was also her witty perky self. She was often furious at the sick white blood cells, angry that she could not do all the things that she had planned for in her future. However, as I described earlier, she was rarely anxious once

her oncologist confirmed the truth. She was rarely self-pitying even though every day she witnessed her big sister going off to school, having playdates, having a future. Often, she would initiate talking about her dying. I tried to help her clarify what she envisioned death was. She had a very clear notion that death was when all your breathing, all your feelings stopped, but she imagined a Heaven where she would be with her two grandpas and other children who had died. She asked if we would be able to talk to each other after she died. Hearing of her Heaven and knowing that she needed a sense of our remaining connected (though I did not share that belief), I said, "Yes though not the way we do now, more with our feelings and our hearts than our voices." She thought up all the good things about dying--no more pain, no more blood tests, no more medicines, no more MRIs, no more vomiting and on and on in a stunning catalogue of the assaults brought on by her illness and its treatments. When she asked me pointblank if I would die right after her, I said, "A part of me will die with you and a part of you will always stay alive with me--and we will always be together in our hearts," and we touched hearts to show where.

Through these times, there was hospice. When K's pain broke through her morphine and she lay moaning, her pain doctor would actually come over or manage it with us by phone whatever the hour of day or night. The hospice team members visited weekly. At first, I felt awkward about this--having relative strangers in our home during this most emotionally and physically intense time. That changed quickly as I saw how empathic they were, how ready they were to go with whatever was happening, whatever was needed. K's counsellor spent an hour with her in the bathroom one crampy afternoon and then took G out for ice cream. He helped each of them to clarify what they wanted from us and each other now facing K's death. It was possible only in our conversations with our counsellor to talk about and to clarify what we could and could not control in K's suffering and to frankly anticipate what was to come. These discussions helped me to accept that I would do what I could but that K might not die on my lap--through no fault of mine. We were able to explore the various ways K might die. She could go into a long-lasting coma. She could have seizures. Would we want intubation? It was through this candor that I was able to steady myself for K, G and C--to ensure that we were not each alone in this agony. The hospice team had not known and loved K as we did. Still, they were able--unlike Dr. S.--to tell us the signs of her deterioration and then acknowledge them when they occurred.

K did make it to her 6th birthday--a "happy sad birthday," as she put it. However, within days, she lost stamina and interest in food. She insisted I be near her at all times. I understood these to be indicators of her final days, however long they would be. Also, I appreciated K's concern about abandoning us and her need to know it was okay to let go when she could no longer fight. That week, as I was sponge bathing her, K said, "I am tired, so so tired. Why must I keep fighting?" I told her that I did not want her to die but that I knew she had to, that I would be okay because I would always have her in my heart and she would always have me in hers. After that, she seemed more at rest. I stayed with her all the time--we all did. Two days before she died was G's 9th birthday and K was determined to live through it, to honor her sister--"She is my big sister"--and she did not want to dampen G's celebration. I carried K to G's favorite restaurant to have a family dinner out. On the way, she said, "This may make me feel more in pain and upset

but I am not going to let that stop me. This is for G.” That evening, K gave G a neck rub. G was glum. K told her she understood that G was upset about her dying.

The next day--the day of G's party--K was flushed and short of breath. In collaboration with her pain doctor and hospice, we worked to help her to stay as comfortable as possible. I stayed with her while C, my mother-in-law and some of our dear friends took G to her bowling party. K and I spent those hours together with few words, with K on my lap, clutching onto me--just onto life, really-- until they would return. That evening, her pain doctor came over to give her additional IV medication for the retching that had begun. It was then that K was told that it was soon her time to die. She said, “I knew that already-- I knew it inside me.” She had already asked for that lullaby tape to be played. That was when she queried, “Why didn't Dr. S. tell me?” Our wise pain doctor ad-libbed that he had sent her to say so. instead. K told G, “It is my time to die and I want you to know that I love you.” After a few more moments, K said, “Now ready,” and became comatose in my arms.

Death

K lived for about 8 more hours with more and more irregular breathing, as we laid her on our bed between C and myself with G draped over her. Her pain doctor came over again--just to give us support. We all held her as she took her final breaths. Then we bathed her and changed her into her favorite pajamas. We sat with her while family and friends came over.

The funeral home arrived to take her away. After she died, at a memorial service, there were hundreds of people who attended, including several doctors from the cancer center.

So--we were lucky. Not at all lucky in K's getting leukemia and then dying from it, not at all lucky in her suffering. But once that leukemia was resistant to all treatment, once it was inevitable that she would die, we were extremely fortunate in how she died. K had the death she wanted. We all had the good good-bye with her that we had hoped for. I believe we have hospice to thank for that. K's death might not be the kind of death another child or adult would want. It was K's death, K's design, and completely in keeping with who K had always been, who we had been as a family. It was not that she did indeed die in my arms that made it a good good-bye though I am deeply grateful that she did. Rather, it was our taking the opportunity to really be together in an emotionally open way during all her days before that last breath that made it right for us and made it a good goodbye.

Death from illness is not pretty or peaceful or easy. The emotions are intense. The anger, the fear, the sadness, even the laughter--of which we had plenty--are all heightened to almost unbearable pitch at times. I felt a need for constant vigilance to ensure that I did not fail her in easing her suffering and to ensure there were no unnecessary moments lost in her dwindling life--as I, all

the while, was working to try to let her go. We were fueled by K's trust in us. For me, providing her painful medical interventions was feasible because I needed to be helpful, needed to know that I was making a difference in her comfort and survival. It was, is, and always will be unbearable to me that I could not save her, could not protect her. I would do just about anything to have K alive. Nothing can change the relentless reality to which I awaken each day--that she has died. However, I do find comfort in knowing that she had the death that she wanted and that we mobilized together to deal openly and honestly with what K was facing--never leaving her emotionally alone.

Afterwards

I had promised K that I would always remember her. What started out as that promise has become one of my most sustaining comforts now that she is gone. During K's illness, many people commented to us about how hard it must be to manage all the medications and IVs and machines. I said then, as I do now, "That was the easy part. Learning to live without her is the hardest part." I do remember K of course, but the kind of real inside-the-heart remembering that sustains me took time. At first, I searched ceaselessly for external confirmations that she had existed, had mattered to others, that she had left her imprint on the world. At first, I searched ceaselessly for external confirmations that she had existed, had mattered to others, that she had left her imprint on the world.

Then, slowly, those outside connections to her became less urgent. I could feel the enduring power of all that she had taught me, all that I had learned about myself and the people I love as we traversed this most awful part of my life. I realized that the worst time was also--in its' intensity and intimacy--the most meaningful time. I learned that I could go forward with my life and simultaneously embrace who she was. It is in tribute to K that I want to help others as they face terminal illness and loss. I now devote much of my lifework to dealing with death and dying. Many people could not talk with us about K after she died. When any mention of her name would have been music to my ears, such people ignored the topic or avoided us. As a society, we are so frightened by death that we distance ourselves from those who are grieving. Then the loss feels all the more unbearable and unresolvable. But for me, grief is about living--finding my way not to move on, but to move along with all that K meant to me. At first, I searched ceaselessly for external confirmations that she had existed, had mattered to others, that she had left her imprint on the world. Shortly after she died, a celebrated singer with a name similar to K's was performing on Broadway. NYC taxis had signs atop with neon letters saying the name of her show. It meant so much to me to see those signs.

Questions & Answers

In the course of symposia and Grand Rounds presentations, these are some of the questions I have been asked:

What was the impact of K's illness and, later, her death on your marriage?

C and I are both analysts and psychiatrists. C, additionally, is a child analyst. We've been through analyses so we are accustomed to understanding feelings and their dynamic elements. We knew right away that we were going to be separated by K's hospitalizations. So, we began with that understanding, knowing that we needed to find ways to stay connected. We set up a plan that every Friday afternoon we would have 2-3 hours when it was just us. That sustained our sense of our existence as a couple. It kept us a team. Also, we kept a notebook by K's bed and would write down notes to each other about the day. They were, at times, almost like love notes. We saw at the beginning how essential it was for us to preserve our marriage. We knew how risky severe childhood illness could be for a marriage. We knew that we had to work very hard to keep together.

Later in K's illness, I worked only one morning a week and C didn't work at all. We went through it together. This was especially hard when K's sleep-wake cycle was reversed.

After K died, we grieved differently. I was grieving the whole time she was dying. I sob privately. C can sob in front of others. I wanted to get pregnant again. He was terrified. I was close to 40. Also, G wanted another sibling. So, C and I were not in synch on that. We spoke with a counsellor for 6 months and came around to trying. A year-and-a-half later, our son S was born.

Was their guilt?

When she initially got sick, I wondered guiltily if I had done something when I was pregnant. Did I do something when she had early treatable childhood asthma? Did our living a block from a dry cleaner contribute? Did I pass a gene from my mother who had had acute myeloid leukemia. We considered our guilty feelings and addressed them by researching the literature and speaking with doctors. They took out charts and showed us data. That was very helpful. Neither of us struggled with much guilt after she died.

Were there recriminations between you?

No, none at all. C was a remarkably involved, caring Dad. It wasn't that we agreed on everything, but we trusted each other.

Did either of you experience a strained impatience with the other?

No. Only once we had a fight, as I recall. She was in the hospital and we were changing shifts. I was passing the baton to C. And we had some fight about something. I don't remember what it was. I stepped back and said, "What are we doing? What matters?" We fell into each others' arms. We knew we were both doing the best we could.

Did either of you experience loss of libidinal interest?

Sex became very secondary. It was all so exhausting. We were affectionate, but sex really occurred once in a blue moon. . . . But that came back!!

Did you compete with each other for being the most compassionate?

No, not about that. With our son T we were competitive about who could give more. T was born one-and-a-half years after K died. Who could give more to him? Who's got more with him? We both went to all the soccer tournaments and chess tournaments. He says that he had a terrific childhood. He was a gifted kid and got along well in every dimension—academic and social. In college, he had a more difficult time. He may have felt with us that he was almost too important.

Did you experience competition with each other to be the K's primary object of affection?

I don't remember feeling that. C and I have different strengths. He'd give her massages and it was the most beautiful thing. I'd make up songs and stories. C was in awe of my being able to do that. She made each of us feel we were contributing to her welfare. She had the grace to appreciate all we were doing. Because of that, the sense of family unity was affirmed, emphatically. We survived her illness as a family because she helped us survive.

Did G and T experience envy or the haunting sense of their sister, a sister G had known, a sister T never had?

During K's illness, we made her feel that the world stopped for her, too. G was in 3rd grade when K was dying. She was attending an elite private school. We explained to K that we wanted to go to G's class to help them understand her situation. K was furious. We went anyway. We went to her class and explained to the class that G had a sister who was dying. K insisted that it was her private matter. But we explained that this also affected G. After K died, G grieved intensely and didn't attend afterschool activities for six months. They had been very close. They had shared a room. They played together. It was a really big loss for her. Some people kept her friends away which created another loss for her. Years later and for a long time, she was afraid of loving someone romantically because of the fear of losing again—she was afraid of feeling that pain again. She is now married and doing well.

What kinds of psychic adaptations (defense mechanisms) were brought into play by you and C?

I am almost incapable of denial. When things were going on with K, I could see what was going on. C was slower to come to seeing it all for what it was. I felt I had to be super Mom. I guess you might say it was modified non-pathologic manic defense, taking control aggressively.

Do you have K's photograph displayed? How?

After K died, I put together two patchworks of photos of all of us at different ages, all randomly placed, haphazardly. They show when K was well, when she was sick, at different points in the life of the family. They were photos of the entire family. So, those two collages are in the apartment. Those photos are there, part of the fabric of our lives. They are just there. For several years after she died, every year we would loft a helium balloon with the image of a Disney character on it. (K was a Disney character lover.) When he was two-and-a-half, T wanted

to be the one to let the balloon go aloft. “This is for you, K,.” he said. C and I thought, imagine, a two-and-a-half year old letting go of a lovely helium balloon! Later, when T was asked how many sisters he had, he would answer, “Two, one is alive and one is dead.” The reader is referred to “We Are Seven” by William Wordsworth, <https://www.poets.org/poetsorg/poem/we-are-seven>.

Conclusion

Embracing the suffering of the slowly dying loved one, and finding the courage and fortitude to do so, and bearing the loss, and mourning the loss, are the greatest and most terrible tasks each of us must face in our lives. This is the story of K and our family. She is gone and she is with us.