

Special Article

Liza's Death: A Personal Recollection

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I will describe the life-threatening illness and then death from that illness in a child, my own child. I do so as a mother who also happens to be a physician. I do so for her—my daughter Liza Carolina Lister. She died just 12 days after her 6th birthday, 4 years ago. She wanted the many professionals involved in caring for the sick to understand—even learn from—her experience. I carry on for her, since she cannot.

I am an adult and a child psychiatrist and analyst in a medical school faculty. I have been married for 16 years to my husband, who is also an adult and a child psychiatrist and analyst. We now have a 13-year-old daughter, Molly, who is thriving in 7th grade, and a 2 1/2-year-old son, Solomon, who is busy exploring every nook and cranny of our home.

Liza's first symptom was pain in her "tussy." She developed it on the eve of her 4th birthday party. It was 12 days later, on Halloween, that we were admitted to the hospital and began the month-long chemotherapy induction for what was found to be acute lymphocytic leukemia. We felt lucky—she began treatment strong, very anemic but with normal platelet and white cell counts. She had all the predictors of cure. From the beginning, my husband and I rearranged our lives so that one of us could always be available to Liza or Molly. Liza's induction was relatively uncomplicated except for a gram negative pneumonia and she went into remission right on schedule.

That was perhaps the last uncomplicated thing her disease did.

After a brief few weeks on chemotherapy back at home, Liza spent the next several months in the hospital with repeated bouts of fungal sepsis and L-asparaginase-induced hem-

orrhagic pancreatitis. It was a series of ICU, crises, pain, innumerable biopsies and scans, huge IV access problems. This was our real induction into the world of her pain, weakness and social isolation—and into the daily uncertainty of her survival. For 50 days, she was too ill to receive any chemo. The subsequent 5 months of outpatient chemotherapy seemed stable only by comparison. We were living with this illness, revolving our lives around maximizing and normalizing our lives, trying to find our fun amidst the daily medicines, dressing changes, hair loss, belly pain, fatigue, and inability to go back to school.

It was during this time that Liza, then 4, first brought up that she thought about dying. She did not want to die, she said, because she did not want to have to be apart from us. I told her that I would not leave her, that we were fighting this big sickness with all the good powerful medicines. I was emphatically hopeful with her and told her that she would grow up big and strong, because it was possible.

Then, Liza relapsed while on chemo, after only 8 months of remission. Her hospitalization for high dose chemo reinduction coincided with the death of her grandpa, my father. He had spent the last 4 months in a cardiac ICU and died without the benefit of hospice.

For Liza, the odds had changed. We scrambled to learn as much as we could, as fast as we could, to speak to experts across the country, to weigh our options carefully. Our best hope was bone marrow donor transplant. Given Liza's multiple complications, we changed our care to a major cancer center, even though it meant a new place and unfamiliar people.

After exhaustive testing of relatives near and far, we had no related donor match. As we waited for a donor from the National Registry, Liza went back into remission. This good news

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was tempered. She spent those months mostly in the hospital for pancreatic pseudocysts huge enough to suppress the splenic vein and cause gastric varices. She also had bouts of sepsis and endocarditis.

Finally, at 5 years, 2 months old, Liza was stable enough and we had a “4 out of 6” matched donor—our best hope. We proceeded with the protocol just as another relapse was discovered.

Liza spent the next 3 months in the high-risk bone marrow transplant center at the cancer hospital. She was in a sterile isolation cubicle and we could have no skin-to-skin contact. Phil and I took turns sleeping at the hospital, but now we “slept” in surgical garb—mask, cap, gown, double gloves, booties—so that we would not contaminate her environment. Fortunately, a very compassionate doctor allowed us to set precedent by sleeping in that cubicle with her. This made a huge difference in Liza’s physical and emotional welfare.

Liza’s transplant engrafted and once again we gratefully returned home. Life for Liza was severely limited, however. She had significant graft vs. host disease, and after careful deliberation, we agreed to allow her to receive an experimental immunosuppressant. In all, she took 40 medicines a day, had daily catheter line changes, and received psoralen-UV light treatments thrice weekly. She developed diabetes and briefly had seizures from her medications. We were in the hospital more than at home during the ensuing 6 months. It was harder and harder to have anything like normal life as the consequences of Liza’s illness and its treatments became more and more debilitating.

We still enjoyed much, however. Liza loved books and words. Reading became a survival technique that saw us through many CAT scans and procedures, as well as pain and fevers. When Liza was up to it, we built castles and police stations, and played games. Molly wrote Liza letters and came to visit each weekend. No matter how ill Liza felt, the girls spoke on the phone daily, at least to say good night. When we were all able to be at home, we maintained life’s routines—baths to be taken, homework to be done—and at times broke some of the rules to maximize family time. We lived with the knowledge that the war was far from over but we were going for cure. Cure was still possible.

Throughout those 20 months before Liza was terminally ill, we had dealt with her and her ill-

ness in carefully thought out ways and observed her coping. We knew that she was bright, perceptive and articulate. She was “heartful.” Remarkably able to name feelings in herself and others, and to face facts, she had always been a need-to-know kind of person. She also needed to have others know her, using words with study and precision to convey her experience to people. Yet, she was also a person who cherished control of her privacy, and we worked to preserve that amidst the manifold intrusions and indignities of being a patient. Liza was also a determined, and sometimes quite stubborn, fighter, wanting control of her life from an early age. We found ways to give her reasonable control whenever feasible and actually had few struggles over taking her medicines, changing her dressings, undergoing blood tests and insulin shots, and restricting foods and activities. Liza seemed to know that it was essential or we would not be asking her to do it. She saw herself as active on her own behalf, fighting those sick white blood cells.

We were, and still, are blessed with family and many dear friends who became lifelines for each of us. However, there was a dearth of formal support. The social work and psychology 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, and able to speak up and ask questions even though we were overwhelmed, anxious and exhausted. That we were physicians was both an asset and a liability. We were informed consumers, not intimidated by medical authority, and Liza was a vocal advocate for herself. On the other hand, we were every parent’s worst nightmare and some physicians identified with us so strongly that they were scared to get close to us.

With little formal support, we pieced together our own network. We sought out other parents and families in similar situations. The hospital team did help with arrangements for IV’s and dressings at home. We found counseling independently for ourselves. This counseling was a tremendous help in sorting out our feelings and learning how to help Molly and Liza cope. This network we developed was helpful in many ways, but unfortunately, there was no sense of cohesion, no one person or even organization overseeing Liza’s care. That was up to us and it was a daunting challenge.

Six months after her transplant, Liza relapsed again. Again, we knew it before it was confirmed. Liza began having more pain in her head, her shoulder, and her hip, and something in the quality of that pain and the look around her eyes told me that the leukemic cells were back in force.

Liza was admitted to the hospital for evaluation and control of the pain. Upon admission, we understood that the possible causes included relapse, fungal infection in her bones, and steroid osteolytic damage. Her scan revealed diffuse bone lesions and several biopsies were done. The following day, Liza's main transplant doctor came in, said a friendly hello to Liza, and then asked Phil and me to step out of the room. As soon as the door closed behind us and as we stepped into the hallway, she said, "The leukemia is back."

She had clearly known for hours and had arranged a room and time for us to talk. For the next 2 hours, she sat with us as we asked questions and sobbed. Our immediate questions focused on her clear and definitive statements that they had nothing else to offer Liza for cure, that she would die, anywhere from 2 weeks to a year from then. We explored chemo and any other treatment options, talked about getting home as soon as possible, and discussed how to talk with Liza and Molly about this. She did mention that there was a "team" who dealt with terminal care, but it was a Friday afternoon and we would not be able to speak with them until the next week. There was no mention of hospice. Liza's oncologist was away but she had spoken with him and arranged for us to do so over the weekend. She offered to come in herself over the weekend even though she was not on call, to answer any questions Liza might have.

Dazed and overcome though I was, I felt her compassion. She showed us her angst and that helped me. I thought that she did all that she could, except for conveying information about hospice. Because we had a good relationship with her from the beginning, she was the right person to tell us. She had often impressed me with her clinical acumen and had always strived to understand Liza and us. She was able to maintain her capacity to guide us while showing us her distress. To me, that is truly "physicianly."

During those early days of living with termi-

nal illness, we again scrambled to find out all there was at this stage, to uncover whatever options existed. We felt absolutely clear that we wanted Liza to be at home with us as much as possible. We felt absolutely clear that Liza should be as comfortable as possible. We knew that Liza would know that she was going to die even if we did not tell her and that we would not leave her emotionally alone with anything she had to face. We anticipated that Liza would want to fight for as long as she could. Having lived on the edge of life for a third of her life, Liza found profound meaning in life.

The year before, Liza had discussed with an adult friend of ours whether the friend's son should be allowed to get an iguana. The friend was ambivalent because they could only be kept a short time before they have to be given away. Liza's response was telling: "Yes, get the iguana. It is worth it to enjoy it for as long as you can even knowing you have to say goodbye to it." We were prepared to fight with her, to value and enjoy whatever we had left together.

And, so, we desperately needed people with heart, smarts, experience and dedication to face this with us, to help us know what else we needed. I did not know it at the time, but I was describing hospice.

Now Liza was no longer considered a transplant patient. At a crucial time in her care, we were shifted back to her oncologist, a physician who was known to us but had not been with us since the year before. He was caring and diligent, and clearly smart, but also did not know or understand Liza as well as her transplant doctor did, and was acutely uncomfortable facing her terminal illness. For Liza, this was a grievous error.

On the day we learned of the last relapse, Liza's transplant doctor went into her room and told her, with us there, that the leukemia cells had come back. Liza listened somberly but did not ask for elaboration until she and I were alone together later that night. As we were preparing for bedtime, she began to ask her questions. "Will I always have leukemia?" "Will I die of leukemia? Will I die soon? Will I get to be a teenager?" Even before I attempted to answer, it was clear that she already knew the answers. I told her that we would do everything we could—anything she wanted us to do—to help her to live as long as possible, to kill those sick white blood cells. She leaned on my shoulder as I knelt beside her. "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 won't get to have babies. I won't get to be a leukemia doctor."

Right then, she immediately began to detail for me how she wanted to die. "I want to die on your lap. I want to have my lullaby tape on. I want you to die with me. No, I want you to die right after me so that you can be with me when I die." Then she asked, "How will I know when I'm dying?"

I promised her that I would be with her no matter what and arranged for her to ask her questions to the doctors. She spoke to one physician who was quite able to face her directness, but responded with shocking insensitivity, analogizing her fear of dying to how her healthy children feel when they hear thunder. When we spoke with her oncologist, he tried to be vague with Liza. As she asked her 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?"—he visibly squirmed and kept telling her 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, and that he would tell her. Finally, he did say that she would not live till her 7th birthday and that he hoped she would live till her 6th. For our child, stark and unbuffered though that conversation was, it was reassuring. She knew the truth, knew we knew it, and needed to know we could all know it together. After that talk, Liza was less anxious.

Sadly, the oncologist did not fulfill his promise to her. When she began to deteriorate, he said nothing. On her final night, when we all acknowledged together that she was dying, even though his promise had not been mentioned in the intervening three months, Liza queried, "Why didn't the doctor call to tell me?" It really matters that physicians be able to face what patients have to face.

After the relapse was diagnosed, we arranged to go home. Her medicines were pared down to just the most essential and all the IV medicines were done at home. We agreed on palliative chemo to give her as much life and comfort as possible. Liza wanted chemo even knowing that it would put her at risk of infections that might require hospitalization, and make her lose whatever sparse hair had begun to grow back. In the conversation with her on-

cologist, she had emphatically stated this to him, then asked, "Do you get it?" When he said "Yes," Liza said to him, "Then repeat it back to me please."

Liza yearned to go back to school. Although this was not feasible—she was so bloated that she could barely walk, and was too sedated by her pain medicine—we arranged for a home teacher.

I got the phone number of hospice through the hospital social worker. I remember that first conversation with our hospice team leader very well. She elicited a history from me with all the facts, but also tried to understand who we were as we faced our daughter's death. I got off the phone and felt for the very first time that we had a net to catch us, a knowledgeable, unflinching overseeing presence to guide us.

The hospice team devoted itself immediately to figuring out what our needs were, and what needs of ours were not being met. They queried us about needs and concerns that we had not even articulated. Their quest was to individualize what they offered and provide what Liza wanted and needed in her dying. They assessed what we as parents were capable of handling and how they could help us do so. They took in the whole picture—medical, emotional, spiritual—and devised a plan.

The team leader met with Phil and me weekly. She also came to meet Molly and Liza, so that she could know them. A counselor was assigned to meet with Molly and with Liza and planned to continue the relationship with Molly after Liza died. A nurse visited weekly, and more often if our needs changed. Astonishingly, the team recognized the importance of my mother-in-law and our babysitter to Liza, and they planned to be available to them as well.

The hospice program could have offered us medical equipment and care. But Liza had always been clear that she wanted me to do all of her IV changes, dressings, injections, and medicines, even if they were "hurty." Wrenching though this was for me, I was determined to continue to do so. Nonetheless, hospice medical care was there for us if we felt we could no longer manage.

The pain doctor we had met at the cancer center was also available and began to work within the hospice model. She was remarkably compassionate and caring, unafraid to talk with Liza about her pain and about her dying.

She, too, saw her mandate as caring for the complete person.

During her final 3 months, Liza remained on her chemo. She had a few weeks during which her pain was eased and she was more alert and mobile. Phil and I stopped working completely. We tried to do some of Liza's favorite things. One of my cherished images from that time is of Liza on her bicycle with me running to keep up behind her connected by her IV tubing (holding her morphine pump). She pedaled with sheer joy at the simple capacity to do it. Food and activity restrictions were no longer useful, and we cooked some of her favorite foods, went to the movies, and to a ceramics studio that she loved. Liza was determined to learn to read before she died and she worked diligently at her homework, practicing her letters.

At times, she was so sedated that it seemed that she was already gone. She often slept stuporously till mid-afternoon and then stayed up all night. At other times, she would be her more usual self, witty and perky. She was often furious at the sick white blood cells, angry that she could not do all the things that she had planned in her future. She was rarely anxious, once her oncologist acknowledged the truth, and rarely self-pitying even though she witnessed her big sister going off to school, having play dates, having a future.

She would often initiate conversations about her dying. I tried to help her clarify what she envisioned death was. She had a very clear notion that her breathing would stop and that all her feelings would stop. She imagined a Heaven where she would be with her two grandpas who had died and other children who had died of her sickness also. She asked if we would be able to talk to each other and I said, "yes, though not in the way we do now: more with our feelings and our hearts than our voices." She thought up the good things about dying—no more pain, no more blood tests, no more medicines, no more scans, no more vomiting, and on and on and on in a stunning catalogue of the assaults of her illness and its treatments. When she asked if I would die right after her, I told her that a part of me was going to die then and a part of her would always stay alive with me. I told her that we would always be together in our hearts.

Hospice and the pain doctor provided cru-

cial support. When Liza's pain broke through her morphine, her pain doctor would actually come over or manage it by phone whatever the hour of day or night. The hospice team members came to the house weekly. At first, I felt awkward about having strangers with us in our home during this most emotionally and physically intimate of times. That changed quickly as I saw how empathic they were, how ready they were to go with whatever was happening, whatever was needed. Liza's counselor spent several hours with her in the bathroom one afternoon and then took Molly out for ice cream. He also helped each of them to clarify what they wanted with us and with each other now.

In conversations with our counselor, we tried to speak about what we could and could not control in Liza's suffering and in her dying, and frankly anticipate what was to come. Her physicians tended to get vague when we explored this. I had become terrified of not being there when Liza was actually dying—in her final moments. These discussions helped me to understand that I would do what I could, but that Liza might not die on my lap through no fault of mine.

We were able to discuss the various ways Liza might die. She could slip into coma, or have seizures. We spoke about what we would do if specific things happened. It was through this candor that I was able to steady myself for Liza, Molly and my husband. When we could talk about this with our counselor or others, we felt that we were not alone in this agony, even though they had not known and loved Liza as we did.

Liza did make it to her 6th birthday—a "happy sad birthday" as she put it. However, within days after, she lost stamina, lost interest in food, and insisted that I be near her at all times. I understood these as indicators of her final days. Thanks to hospice, I appreciated Liza's concern about us, her fear of abandoning us or hurting us, and understood her need to know that it was okay to let go when she could no longer fight.

That week, Liza told me she was tired. "I'm so, so tired. Why must I keep fighting?" she asked. 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 that she would always have me in hers. After that, she seemed to be more at rest, less angry somehow. I

stayed with her all the time. We all did. Two days before she died was Molly's 9th birthday and Liza was determined to live through it, to honor her sister—"She is my big sister"—and not ruin the celebration. Liza was carried to the restaurant to have a family dinner out. That evening, she gave Molly a massage because Molly was glum, saying to her that she understood that Molly was upset about her dying.

The day of Molly's party, Liza was flushed and short of breath. In collaboration with her pain doctor and hospice, we worked to have her stay as comfortable as possible. I stayed with her while Phil, my mother-in-law, and some of our friends took Molly to her party. Liza and I spent those hours together with few words. Liza on my lap just clutching me, clutching life till they could return.

That evening, Liza began to vomit and her pain doctor came over to give her additional IV medication. That was when Liza was told that it was soon her time to die. She said, "I knew that already." We connected this to her having asked for her lullaby tape an hour before, but she said, "No, I just know it inside me." Liza told Molly, "It is my time to die and I want you to know that I love you." She asked for her babysitter to come over.

After final moments, Liza said "Now ready" and in my arms she became comatose. She lived for about 8 more hours with more and more irregular breathing, lying on our bed between Phil and myself, with Molly at her feet. Her pain doctor came over again, more just to give us support. We all held Liza as she took those final breaths. Then we bathed her, changed her into fresh pajamas and sat with her while family and friends came over before the funeral home came to take her.

We were lucky. Once the leukemia was resistant to all treatment, once it was inevitable that Liza would die, Liza had the death she wanted, and we all had the good goodbye with her that we had hoped for. I believe we have hospice to thank for that. Although her death might not be the kind of death another child would want, or another grown-up would design, it was a good goodbye for us because we were together in an emotionally open way during all the days before her last breath, not just because she did indeed take her last breath in my arms.

What hospice offered was a responsive network, an individualized plan that did not re-

quire us to leave our medical care or change what we did not want to change. Hospice filled in where the existing medical system could not. The members of the team knew that each death is unique and they did their best to help us make Liza's death a death with dignity, a death in character, and a death with love and especially honesty, because that is what Liza wanted and needed. They made it possible for us to do what was most important to us—be together, be with Liza, and have Liza at home where she felt most comfortable. They allowed us to fight for every bit of her life possible—incorporating chemo into the plan as we all wished—even while helping us to prepare for her death.

Hospice conveyed to us that Liza's care was not over just because her cancer could not be eradicated. This, too, was a phase of her life and they were prepared to care for her—actually all of us—during that time. Most uniquely, hospice did not treat Liza's death as the end of our care. Most of her physicians did and just stepped away. The few who did not were the truly gifted doctors. The nurses from the hospital also did not step away and for that I am grateful. The hospice team however did even more. They came to our house, and came to her funeral. Our team leader even spoke at her memorial service. They continued to meet with all of us for many months after Liza died. That ongoing presence helped me to process living without her and also gave all of us a sense of her continuity, young and isolated though she was. Our counselor met with us until her own death just a year later.

Death from illness is not pretty or peaceful or easy. The emotions are intense. The anger, the fear, the sadness and even the laughter, of which there was also plenty, are all heightened to almost unbearable pitch at times. Liza's ongoing medical care was demanding. While carrying the emotional weight of someone you love dying, constant vigilance also is necessary to ensure no failure in the easing of suffering, and to ensure no unnecessary moments lost in a dwindling life. You are called upon to maintain someone's daily life all the while you are working to try to let go. We were fueled by Liza's trust in us and by her fervent preference to have us do all medical interventions possible. For me, this was important because I also needed to be helpful, to know that I was mak-

ing a difference in her comfort and survival. It was, and is, unbearable to me that I could not save her, could not protect her. At least, I could ensure that her medical care was carried out as she wished. My medical training made this easier for me than it might be for others.

I would do just about anything to have my daughter alive. Nothing can change the relentless reality that she died. However, I am comforted, knowing that she died the death she wanted. I see that as wholly the outcome of mobilizing together to deal openly and honestly with what Liza was facing, of not leaving her alone with her dying. Not all of us will be that lucky.

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Commentary

Improving End-of-Life Care: Listening to Voices from the Trenches

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I met Phil and Elena Lister at a psycho-oncology conference where Elena was speaking about their daughter, Liza. I was struck then, as I am now, with Dr. Lister's capacity to describe the collective family experience when facing an ill child who is dying. We benefit from this perspective, which is that of a parent shaped by analytic training. It provides us with very thoughtful insights into the world of a family living through the death of their child.

We also peer through a window of rare privilege, able to hear the thoughts of a child facing

death. We were able to learn from Liza that it is difficult to talk about dying, but listening to worries and responding to them honestly can bring comfort rather than increased anxiety. Liza's family somehow knew this and found a way through their own distress to respond to her poignant questions; "Will I die soon? Will I get to be a teenager?"

Care for such a child and family can be a great challenge: How can a child and family feel that they were well supported despite the sadness and profound loss? When lecturing about pediatric palliative care, I sometimes show a slide of a man carrying a coffin up a very steep hill. I use it to emphasize that the path of illness leading to death sometimes cannot be changed, that caring for a child who dies is hard enough without adding to parental distress through interventions that do not make a difference. Dr. Lister describes what she viewed as helpful and what she feels could have been improved. The provision of "formal support" was lacking, something that the Listers found for themselves. As I have heard one parent express, "I had a lot of support at the beginning and I know there will be support should my child die but I don't know how we're going to get through this next part."

One critical aspect of care is how the child's symptoms are assessed and managed. Hearing that Liza was ultimately able to live with the best quality of life until her death is a very welcome portrayal of what is possible with excellent end-of-life symptom management. The principles that ensure quality of life must be incorporated throughout the child's lifetime and throughout the illness, not only at the end-of-life. It is only recently that the protocols that prescribe the chemotherapeutic plan for adults living with cancer have incorporated quality-of-life and symptom distress measurements as an important aspect of the outcomes measured. Cancer care for children still largely lacks this consideration. As recently documented by Wolfe et al., children with advanced cancer often have significant inadequately relieved symptoms.¹ This can be improved if clinicians become educated in the many available techniques for symptom control. We also need to develop new strategies for symptoms that respond poorly to the current modalities. The crux of the matter is emphasis and interest. This component of care can and must be en-

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