GUEST ESSAY

If My Dying Daughter Could Face Her Mortality, Why Couldn't the Rest of Us?

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The first week of March 2022, I flew to Miami with my 13-year-old daughter, Orli; her 8-year-old sister, Hana; and my partner, Ian. We were, by all appearances, healthy. Robust, even.

In reality, we were at the end of a reprieve. Orli's liver cancer had by then been assaulted by two years of treatments — chemotherapy, a liver transplant, more chemotherapy, seven surgeries. Now new metastases lit up a corner of one lung on scans, asymptomatic but foreboding. We asked her medical team if we might show her a bit of the world before more procedures. Our oncologist balked. Hence, this brief weekend away.

When we arrived at the beach Orli ran directly to the water, then came back and stretched out on a lounge chair. She turned to me and asked, "What if this is the best I ever feel again?"

Three hundred and seventy-six days later, she was dead.

In the time since she left us, I have thought often of Orli's question. All that spring, Orli asked, pointedly, why did we think a cure was still possible, that cancer would not continue to return? Left unspoken: Was she going to die from her disease? It was a conversation she wanted to have. And yet what we found over the wild course of her illness was that such conversations are often discouraged, in the doctor's office and outside it.

What would it have meant for Orli's last year if her medical team had encouraged us to meet her where she was? What if we lived in a society that was able to sit with the anguish that arises for very sick children and their families? In other words: What if we were presented with something other than relentless hope? If we had been asked to really consider that Orli's time on earth was limited, how would we have used that time?

Orli Wildman Halpern in November 2021, age 12 and a half. via Sarah Wildman

Americans — really, Westerners — are terrified of death. We shy away from it. Death is a problem to solve, not an inevitable part of life. As the grief therapist David Kessler pointed out to me, we once visited the dead in the front parlors of private homes. Now the dead are tucked out of sight, handled by others. A bereaved family is the locus of nightmares rather than the focus of shared support.

Nowhere is this more true than with the prospect of a child's death. Death from illness is seen as aberrant, unusual, terrifying. Death from war, gun violence, abuse is lamentable, awful — separate. Healthy children and teens are largely shielded from the critically ill. Visiting the sick, let alone the dying, is associated with the aged and infirm; a charitable act, but not integrated into our ethos. Clergy members are overburdened. Death in America is a whisper, a shame, an error. Supporting a family through the end of life is delicate. For a child, it is also obscene.

In pediatric cancer care, which has an understandable emphasis on cure, advances that have brought families hope can often mean survival rates are downplayed, hard conversations avoided. Death, when it comes, feels like failure. Medical schools rarely insist that students consider the prospect.

If doctors aren't comfortable broaching the subject of death with their patients, the rest of society long ago lost the ability to do so. Ian once quietly mentioned to an old friend that he feared Orli would not survive. She chastised him for giving up hope. He should not say such things. In the time leading up to losing Orli and in the aftermath, we lived on the terrible fault lines between these dynamics.

To sit with a family that has experienced, or anticipates, child loss is to know it cannot be made better. And yet there are ways to better how we face it.

Throughout Orli's illness — from diagnosis forward, and particularly in her final harrowing months — her physical pain was largely addressed. But those efforts were undercut by a terrible absence of emotional support — for her, for us, for Hana. As for how to truly understand the expression "life-limiting illness," we were largely on our own.

The medical teams who worked with Orli were good, smart and, above all, caring. Her community, likewise, was filled with well-meaning people. I worry this may come across as embittered: the bereaved mother, shaking her fist at the sky.

I hope instead it offers a potential corrective. Perhaps part of Orli's legacy is insisting on this conversation.

In the months after that beach trip, life as our family knew it collapsed and reformed, through lung surgery and radiation, a first brain metastasis, brain surgery, more radiation — and then, impossibly, a second brain tumor, surgery and, horribly, more extensive radiation. In the moments between, though, life was still life. Orli got back on a surfboard, read 15 books, ate her favorite foods, danced.

In late September, following a successful second brain surgery — after which Orli won a lead role in her school's production of "Twelfth Night" and joined the volleyball team — she was hospitalized with severe headaches. Her medical team was, at first, intent on getting her off the hospital floor, back to play rehearsals, back to school.

But as days in a hospital room stretched to a week, then to two, the pain did not subside, despite various interventions. One afternoon, a palliative care doctor stopped by and lightly offered what she called a "back door" to home nursing: hospice. Under Obamacare, she confided, children may continue curative efforts concurrently with hospice, a prospect unavailable to adults. (She apparently did not know that, in our case, hospice insurance benefits did not include general home nursing.)

I was driving when a hospice intake nurse called. Orli, I told her, was just about to enter an experimental drug trial, and I understood she was entitled to receive hospice services while continuing curative or life-extending care; she could even leave hospice if she improved. The nurse acknowledged all that was true. But, she added, You know they told me she has six months to live, right?

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No, I said. You're the first to tell me.

After Orli was discharged, an oncologist caught me in the hallway. I heard you didn't finish the hospice intake, she said. I told her the story — the nurse, the car, the prognosis — and asked: Is it true? Does she have six months? She didn't quite answer. That's an antiquated way of thinking about hospice, she said. She did not say: Sarah, we cannot predict when death will occur, but we have discussed that there is no cure. Orli will not survive. Nor did she say: The idea of hospice may inspire panic, but studies have shown it can actually extend life.

I have told this story many times to my sister, herself a nurse practitioner in oncology. Each time she asks: If the doctor had said bluntly, "Sarah, she's dying," would I have been able to hear her? I have told her: Honestly, I do not know. Maybe not. But that's not the conversation we had.

Orli Wildman Halpern the day before her bat mitzvah, Jan. 12, 2022. Miranda Chadwick, via Sarah Wildman

This story might sound ridiculous, even willfully ignorant. It was hospice, after all! Shouldn't I have understood that meant she was dying? But consider: I was assured that for children, hospice is no longer only for end-of-life care.

Doctors know parents of critically ill children are endlessly searching to find the miracle, the untried drug, the new treatment, the expert with a plan that will reshuffle the cards. Hearing "There is no cure" is not the same as hearing "She is dying. She will die," nor is it the same as saying "Death is near." Many of us with terminally ill children need to be told that our child is going to die over and over again to really believe it.

Medical teams are typically reluctant to bridge that distance between reality and hope. A February 2023 study in The Journal of Palliative Medicine on families with children in advanced stages of cancer care found a consistent pattern of soft-pedaling news to parents and patients, of leaving, as the authors put it, "space for hope," with "vague warnings" and "data without interpretation" — meaning that patients and their caregivers weren't given the real shattering news. Many of these patients died during the study.

But not telling families where they are in the process stalls or stymies important conversations. How to live well, even when facing death, requires knowledge.

"It is so hard to get clinicians to even talk about death and dying," said Dr. Tessie October, an intensive care and palliative care physician who briefly worked with Orli. "And part of it is that we spend so much of our energy saving lives that the idea of a life not being saved feels like a failure."

Dr. October noted that one of the children's hospitals she worked at refused to fund-raise for bereavement services when she asked to create a program. It didn't want funders to think children died there.

The prospect of child death may be taboo, even in oncology, but dead and dying children hovered all around us from the time of Orli's diagnosis. They were present in a phalanx of butterflies tacked in their honor to the walls of the department; they returned in the form of toys or blankets or other trinkets distributed to hospital rooms, each affixed with a label of a foundation and the story of a life cut short.

Death rates from cancer among children have dropped precipitously over the past few decades, but cancer remains the leading cause of death by disease among kids. Cancer is not one disease: Orli's cancer, hepatoblastoma, has about an 80 percent five-year survival rate for children diagnosed under the age of 3, but for kids diagnosed over age 5 (who number far fewer), survival rates plummet (Orli was 10 when she was diagnosed). Some brain cancers still have a close to zero percent chance of survival. After Orli's death I ran into one of her oncologists and asked her if she had ever had an older child survive this diagnosis. She had not.

We knew it was never impossible that Orli would die of her disease (Ian often asked her doctors pointedly about the prognosis), but we spent three and a half years stubbornly tracking down experts who dangled the possibility that we would see our way through. The hope that your child will be the one to upend the data set offsets the taxing reality of daily cancer care for both child and caregiver. And Orli herself bounced back remarkably from her liver transplant, from chemotherapy, from surgeries, from bouts of sepsis. Her tumor markers reliably dropped after a surgery or a treatment. Until they didn't.

For cancer families, the transitions between stages of care, from diagnosis forward, are emotionally grueling. Navigating the abrupt shift from curative care to maintenance living — a life extended, but with no known cure — requires an abrupt pivot. Facing the limits of medicine's ability to cure forces medical teams and caregivers alike to hover in a space between hope and acceptance, love and terror. It's also where communication falters.

If a child begins to die, support for both patient and family requires a delicate, coordinated effort between social workers, palliative care experts, oncologists and hospice. Families like ours need both to keep a child comfortable and to brace for worse. Such support is possible. But it takes effort, funding and, perhaps most important, the will to recognize that end-of-life care, and then, inevitably, bereavement care, is essential care in pediatrics. That's rare. We didn't find it.

Two weeks after that "six months to live" conversation, Orli's oxygen levels dipped. Knowing hospice offered home deliveries of medication and oxygen, we called back.

But a baton was dropped in the transition from hospital teams to hospice, which seemed to know little about Orli and was not prepared to help us face the traumatic intermediary space we were in: It was not clear how long she might continue to live on, trying experimental treatments.

My only in-person interaction with the hospice on-call doctor was about five months before Orli died. We were beginning a new maintenance regimen of oral chemotherapy. That day, at my kitchen table, the doctor handed me the long-form equivalent of what is colloquially referred to as a D.N.R. form, or a do not resuscitate form, fully filled out. No one at the hospital had yet discussed eschewing resuscitation with me.

I begged him: Please, let's wait. Though I have begun having this conversation with my family, I am not ready. He proceeded to lecture: Critically ill children should not be revived. Pulling out a piece of paper, he drew a graph with the high point of Orli's life, before diagnosis, and then drew a line on a sharp downward slope. The implication was: Now we are at acceptance of the end. But that had not been her trajectory. It appeared that no one from our hospital team had conveyed Orli's timeline — how she had returned to school again and again, written short stories, how she had gotten on a surfboard after a brain tumor or danced at a Lizzo concert just weeks prior. And he did not ask.

What I wanted him to say was: I'm sorry to meet you. This is monstrous. But time is no longer boundless. How can we maximize these weeks?

Instead he offered the bluntness we needed at the hospital, without the relationship. I later wrote to him, detailing my discomfort. He wrote back, graciously. He said I had made him a better doctor. I never spoke to him again.

Even at the clinic, among those who knew us best, we fell through gaps in caregiving. Just as Orli started to really decline, her favorite child-life specialist left the hospital.

A child-life specialist, as Orli once explained on an Instagram livestream, is neither nurse nor therapist, but someone trained to buoy and guide a child throughout care. In her case, it was the person in the hospital Orli most trusted. We once nominated him for an award he won — airline tickets. He flew to Europe and brought back a Paris sweatshirt Orli rarely removed.

In January, two months after we had enrolled in hospice, Orli ended up hospitalized for three weeks; by then, he was gone. An external intravenous line put in her arm, threaded through a vein near her heart, had brought on an infection of such virulence it caused massive seizures. For days, infectious disease experts searched for the right antibiotic cocktail. Nurses wore yellow paper gowns they ripped away when they left her room, lest pathogens spread.

When Orli finally left intensive care, I went to see child-life specialists at the hospital who she knew, and who, more important, knew *her* — her perspicacity and her wit, her droll cynicism. I wanted someone she trusted to help her face where we were now. Maybe even to consider death. It couldn't be someone entirely new: We were too jaded, too sad, too shocked for that.

I was dissuaded from consulting anyone beyond oncology. One child-life specialist who had worked with Orli said she was explicitly advised not to speak to us. We were assigned a new hire, a chipper young woman who didn't know Orli. She brought with her treacly tones calibrated to a different type of child. Orli rejected her; the woman disappeared.

(After Orli died, I wrote to the hospital ombudsman asking why child life had not shown up for her in a meaningful way. I offered to come in to speak to the teams about the delicacy of emotional needs at the end of life. Nothing ever came of it. The head of child life did not respond to emails.)

Meanwhile, a tumor we'd seen on scans months earlier suddenly compressed Orli's spinal cord. She was unable to stand or walk, and was rushed into radiation. Representatives from the rehabilitation department arrived and suggested Orli might benefit from weeks of inpatient rehab. When I saw our oncologists, I told them: Rehab stopped by. I don't understand. How much time do we have? They said: We're so glad you brought that up. We don't know.

I mulled this over and over: If her primary care team now believed she was actively dying, why had rehab come to see us? Why had I been the one who broached the question of time?

The lack of psychological support in the hospital meant that it was only when Orli was discharged that she truly understood her new limitations: She would never walk from the car to the house on her own again; she would not swing her

legs over the side of the bed and adjust her shelves to her liking; she would not film a new dance; she would not step outside, stand or bathe unassisted. That pain far transcended the physical.

It's worth noting that pediatric palliative and end-of-life care has made tremendous strides in the last quarter-century.

In 2000, Dr. Joanne Wolfe, a pediatric oncologist and palliative care specialist, collected testimony from families of children who had died of cancer between 1990 and 1997 at Boston Children's Hospital and published a major retrospective study of palliative care in children's oncology. The report was devastating: "Eighty-nine percent of the children suffered 'a lot' or 'a great deal' from at least one symptom in their last month of life, most commonly pain, fatigue" or difficulty breathing, they wrote.

Dr. Wolfe's study "really shook the pediatric oncology community" said Sarah McCarthy, a psychologist focused on pediatric oncology and palliative care who lost her 5-year-old daughter Molly, an identical twin, in 2022, to complications from treatment for leukemia and neuroblastoma. The question that began to haunt those in the field, Dr. McCarthy told me, was, "How do we better take care of those patients where the goal is not cure or where cure is not going to be possible, especially in the last weeks and days of their lives?"

Dr. October, the intensive care specialist, trained in critical care in the early 2000s. At the time, she said, "I realized I did not have the skills to communicate empathetically with families at their most vulnerable time." A so-called bedside manner was perceived as something innate, not learned. We now understand better, she said, that the practice of palliative care — of active listening, of being present — requires training.

Palliative care only recently became a medical subspecialty in pediatrics, and insurance coverage for this kind of care is patchy and confusing. Not every critically ill child receives palliative care. And while most everyone agrees that a

child at the end of life should not experience pain, there is ambiguity about the squishiest aspect of that mandate: psychic pain.

In 2008, Victoria Sardi-Brown's son Mattie, then 6, was diagnosed with an aggressive bone cancer. "Mattie was treated at three different hospital sites, and at each hospital site the level of emotional and psychological care that he had access to varied tremendously," Ms. Sardi-Brown told me.

Following Mattie's death, Ms. Sardi-Brown and her husband, Peter Brown, founded the Mattie Miracle Cancer Foundation. In 2012, the foundation organized a symposium on Capitol Hill, where it demanded the development and implementation of evidence-based standards and a minimum level of psychosocial care — from diagnosis through remission or death — for critically ill children. (Palliative care, despite its reputation, addresses quality of life and pain associated with disease throughout the course of critical illness, not only at the end of life.) The 15 standards, published in the journal Pediatric Blood & Cancer, insist upon periodic psychological assessments of both patients and their siblings. They also mandate that "psychosocial professionals should be integrated into pediatric oncology care settings as integral team members."

"The challenge was after these standards came out — and they were very often cited — people didn't know how to implement them," Lori Wiener, the lead clinician and researcher on the standards development team, told me. Follow-up studies noted financial barriers to large-scale implementation; that has begun to change, albeit slowly.

Orli in June 2022, two weeks after brain surgery. via Sarah Wildman

There *are* hospitals doing this well. I first reached out to the neuro-oncologist and pediatric palliative care specialist Dr. Justin Baker, then at St. Jude's, when Orli returned from that last hospital stay. He advocates an integrated, interdisciplinary approach to palliative and end-of-life care for children in oncology that, among other things, pulls in bereaved families as teachers.

Dr. Baker says he is in the "regret prevention business," an idea I also heard from Dr. Wolfe. That means, for example, discussing with a child's medical team what the real drawback of delaying treatment by two weeks might mean, while a child is still well enough to travel. Life experience might be more important than chemotherapy or surgery, which are not guaranteed to extend life (and will certainly make a child temporarily miserable). This is less intuitive than one might think: Doctors are risk-averse.

Dr. Baker, now at Stanford, underscores the need for a family to recognize that time is limited, rather than fighting that limited time. To measure time in teaspoons rather than gallons goes against every parenting instinct. But such recognition can allow more of those final moments to matter.

This work fits with what BJ Miller, a nationally recognized expert in hospice and palliative care, says makes for a "good" hospice. That would be both quick delivery of medication or equipment (which we had), as well as, effectively, "a crew of people," including doctors, nurses, social workers, chaplains, art therapists, even volunteers, skilled at communicating (which we did not). That means, Dr. Miller said, "potentially hours and hours of conversation and processing and reflecting."

This work does not end when a child dies. The St. Jude's program was created with the assistance of bereaved parents like Wendy Avery, whose 15-year-old son Nick died from leukemia in 2006. At the time, she told me, many hospitals had parent-to-parent buddy programs that simply dropped families whose kids weren't going to survive. Ms. Avery is now on a committee that mentors families going through transitions in care, as well as newly bereaved families. It also matches bereaved parents with doctors, teaching them how to give hard news.

"When we were first starting this, there was so much pushback," Ms. Avery told me. "The employees at the hospital, especially the doctors that took care of our kids, felt like they had personally failed our kids." Changing that took time. "Now the program is huge," she said, "and it's very well supported."

Every study on the subject I've read has found that the only way to mitigate the terrible comorbidities associated with losing a child — prolonged grief, anxiety, depression, inability to work, suicide, heart disease, untimely death — is with therapeutic intervention with a family in the time before a child's death and then early, consistent grief work after. Support for a child and her family — including

posing and then facing questions about the end of life, and how to live when life is suddenly bounded — can help a family better face life after a child dies. But investment in this area continually falls short.

This spring, a landmark paper in The Lancet underscored how bereavement care is not a luxury but a public health necessity. Such care, however, remains far from universal. The result is that during critical illnesses families become dependent on a war room of professionals caring for their sick child, only to find themselves abandoned when the child dies. “Given health-care institutions cultivate this dependency on their systems throughout the care trajectory, it should be incumbent on these very institutions to address grief needs before and after a patient’s death,” the authors wrote.

After Orli died, we had little contact from the team we had spent some 1,300 days with: There were text messages from our beloved primary oncologist the day of her death, but no follow-up (until we asked for one, weeks later). A smattering of individual providers mailed us notes, some incredibly moving. The oncology unit sent a card, about 100 days after her death. In late spring, I ran into one of Orli’s oncologists on the street. I told her about Orli’s funeral. She cut in: I was there, she said. She hadn’t wanted to bother me. She didn’t understand how much it would have meant to us to know.

Later, while doing reporting for this story, I found out that the hospital recently held a memorial service for the children who had died in 2023 and 2024, including Orli. No one had contacted us.

Boston Children’s Hospital, where Orli received her liver transplant, is one of a few hospitals that offer continued support to bereaved parents. In the past year we have found sanctuary hours from our home in a family bereavement program at the Hole in the Wall Gang Camp, a project started by Paul Newman

for critically ill children 36 years ago. Such programs are reliant on philanthropy, as well as social recognition of child death, the trauma that preceded it and the lifelong impact of this loss.

I keep coming back to something Wendy Lichtenthal, a lead author of the Lancet paper, told me: Our culture has a profound lack of "grief literacy."

Medical teams may fear death, but so does society, in a cycle of suppression and evasion that ultimately fails us all. It is why so many of us feel so alone when death and grief come.

At one Shabbat we hosted earlier this year, the young son of friends had a question. "There are two children in all the photos on the walls," he said, "but only one here. Why?" The room seemed to stop breathing.

"Yes," I told the boy. "There are two children in the photos, and one child here. It is very sad." I worried: What was I allowed to share? His mother turned to me, concerned. "Will it upset Hana if he asks questions?" No, I said — it's far stranger when no one asks at all. We talk about Orli every day.

I developed a working theory over the course of Orli's treatment that the American ethos that hard work leads to success rendered facing death, let alone dying, incomprehensible. How could we go through something this difficult only to find ourselves, ultimately, someplace worse?

Just before the anniversary of Orli's death, I went on a walk with her middle school administrator. We talked about how, in Orli's final months, I asked her to help me encourage students to call or text or visit. It seemed there was little urgency to see her. Orli had been out sick before; she always returned. How could it be otherwise? In the last days of Orli's life, this teacher took it upon herself to bring groups of girls to our home, in her own car, during school hours. Later, she berated herself: Why hadn't she done so sooner?

In removing death from the rhythm of life, we have created “a grief-phobic and death-denying culture,” the psychotherapist Francis Weller told me.

As a society, we need to reconsider why we are shielding our children — and ourselves — from death and dying, and what we lose when we do. We need to turn toward, rather than run from, the people who know this terrible world best: bereaved parents. To do so would allow our children a means of leaving a mark on this world.

“We need to be taught how to be with grief,” Mr. Weller said to me, “which means we need to witness it as we grow up.” He went on: “And for the most part, we don’t see it. It’s cloistered, it’s segregated, it’s pushed to the side. So when it does show up, we don’t know how to meet it in any meaningful way.”

Recently, a friend of Orli’s gave me a tremendous gift: the knowledge that Orli had tried to prepare herself. Four months before her death, Orli texted this friend to say she knew she would not survive. She believed she had two years left. “I’m going to die,” she wrote. “But doesn’t everyone? I just will die a little sooner than most. This is a great opportunity for me actually. Everyone’s focused on the time they have left. They forgot to live.”

That she could face what we could not is not entirely unusual. Some psychologists have pushed for allowing teens and young adults a role in determining not only the course of their care but also in how they live their days, and how they die. This population, I learned, has a strong sense of their own trajectory; they are known for trying to protect the emotional well-being of their caregivers.

Indeed, after she died, I found out that Orli had worried most about what would happen to us — Hana, Ian and me — if she were to leave. I offered her no reassurance. I didn’t know these were her fears. I learned of them too late.

She and Ian spoke about death more than I did — what happens, where do we go, is there something more, will we ever see each other again? I wish I had been in those conversations. Still, I am comforted that they took place.

Everyone, even children, deserves the opportunity to sit with these questions at the end of life. It's not impossible. But to do so requires us to recognize: It's not sadness we should fear. It's regret.

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