

## The Literacy of Pain

### *Narrating Identities in the Face of Death*

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**ABSTRACT** Following H. L. Goodall Jr.'s call to employ narrative ethnography to help re-establish "the centrality of personal experience and identity in the social construction of knowledge,"<sup>1</sup> this essay examines one scholar's efforts to identify with her student, Anna, during her battle with terminal Ewing's Sarcoma. Using performative writing and the lenses of literary devices and relief humor, we seek mechanisms for grappling with the complexities of life and death: labeling devices and tropes, using what we know to figure out what we do not know, and thinking critically and reflexively. **KEYWORDS** Narrative ethnography; Relief humor; Literary devices; Death; Performative writing

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Have you ever wondered  
If some people will wonder, and wonder  
And wander in realization after reality rests?  
Have you wondered  
If the people will wonder and then  
Peacefully ponder the undying  
Essence of your echo and the  
Silhouette of your legacy that  
Spirits the memory after death passes?  
I have.  
I have so, so, so  
Wondered.

Mattie J. T. Stepanek<sup>2</sup>

Acclaimed peace activist Mattie J. T. Stepanek was a *New York Times* bestselling author before he died at the young age of 13 from a rare form of muscular dystrophy in 2004. Knowing that his life would not unfold like other children his age, he used the little time he had to urge others to seek peace within their communities and within themselves. Adopting the mantra that "We have, we are, a mosaic of gifts, to nurture, to offer, to accept," Stepanek motivated

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countless others to cultivate their connections with each other through their words, deeds, and capacity to hope.<sup>3</sup> Stepanek's journey on this earth, though tragically abbreviated, demonstrated a grace of living amidst dying. His messages of hope, courage, and connectivity parallel our following analysis as a means of reflecting on our shared potential to face our own impermanence meaningfully and compassionately.

In this essay, we offer a narrative account, tracing the relationship between L. Hailey Drescher and her high school student, Anna, during Anna's last year of her life. In co-authoring this essay, we have discussed at length our mutual experiences of realizing the power of death to transform life and the profound importance of being present in the lives of those facing imminent death. While this essay is chiefly about Drescher's account of losing her student and friend, Anna, the assemblage of story fragments and interpretive insights are also informed by Suzanne Enck's own series of familial losses (her sister, mother, and father). We have coordinated in writing this essay, reflecting carefully upon Drescher's involvement in the life of Anna, to co-create a meaningful narrative about larger lessons about living in the midst of death.

In reflecting on and making meaning of Drescher's experiences with Anna, we approach her narrative, their narrative, in an effort to examine the world in which we live "from the perspective of the interacting individual."<sup>4</sup> In so doing, we wish to blur boundaries between the personal and professional, individual and community, researcher and subject.<sup>5</sup> We employ what H. L. Goodall Jr. calls "narrative ethnography," which encourages scholars to center "personal experience and identity" as a means of constructing knowledge in our everyday contexts.<sup>6</sup> In particular, we approached our meaning-making endeavor like "interpretive bricoleurs,"<sup>7</sup> collecting fragments of Drescher and Anna's story together: Drescher assembled old email correspondence and journal entries, and importantly, talked to Enck about her many experiences with Anna when she was thriving, as she was dying, and after her death. In this way, we are also crafting this project in the spirit of Tasha R. Rennels and Blake A. Paxton's analysis of how friendships can deepen through shared experiences about loss.<sup>8</sup> We talked, and perhaps more importantly, we listened, seeking meaning in our shared understanding of personal losses. While dominant grief paradigms suggest that "relationships with the deceased should be terminated," we agree with Rennels and Paxton, who observe that reflecting on relationships with those we have lost can spark "our willingness to continue, rather than sever, our bonds with them."<sup>9</sup>

In the ongoing effort to understand and respond to difficult matters of health, illness, death, and human connection better, we approach this essay by

highlighting some of the same techniques Drescher once taught her high school Shakespeare students: underline and label the devices, use what you know to figure out what you don't, and think critically and reflexively. Drawing upon narrative accounts documented by Drescher in her personal journal during Anna's battle with cancer, we have retroactively examined Drescher and Anna's relationship, aiming to write "about the poetics of living," especially as it relates to our capacities to love, care for others, provide hope in the midst of teaching, and create meaningful bonds with others through our acts of "creative kindness."<sup>10</sup> Ultimately, we have found that some of the most profound work of living is contained in life's subtext.

**17 NOVEMBER 2010—8:15 A.M.**

I heard from my substitute that two of my English III students were mysteriously late to class in my absence. They weren't just a little late, but what I would call perilously late. They were late enough to draw attention and warrant further discussion. Given the names, I wasn't overly surprised: Anna and Sarah. Both girls are sweet and well intentioned (what teachers call "social"). I figured some sort of junior-year party drama had led them to gossip in the hallways. Standing at my duty station, I was inescapable. Good luck trying to get past with your tie undone, your sleeves rolled, or your skirt too short. Teaching high school students at a private Catholic school means that I am paid to care about dress code between the hours of 8 a.m. and 4 p.m. Not only do I write up dress code violations, but I also take great pleasure in asking annoying questions to irk teenagers in my sweet, but mocking tone.

"Brian! Your top button isn't buttoned! How could you possibly be successful when you are not dressed for success Brian?! Your neck might get cold."

I was 28 years old and teaching in a climate where strict social mores met teenage exuberance, and I found that using relief humor was the best way to disarm arguments over minor clothing infractions. Seeking to strengthen and uplift my students, not undercut them, using relief humor became an essential part of most daily tasks in the high school setting.<sup>11</sup> "Anna!" I yelled jubilantly down the hallway in hopes of embarrassing the tall redhead into more prompt attendance. She approached with the shorter, and quieter, Sarah in tow.

"Anna, I heard from the substitute that you and Sarah were woefully late for class in my absence. Anything I should know?"

"No, Mrs. Drescher. We stopped to talk to Ms. Lucas, and that made us late to class. Sorry about that."

I offered my standard soapbox lecture about the importance of punctuality and impression management. The admonishment was more obligatory than necessary. Both girls had always been well behaved, respectful, and conscientious in their work. Anna's most recent paper in my junior level English III course was practically flawless and earned a high A.

"Mrs. Drescher, I'm not going to be in class tomorrow. I've been having some strange hip pain so we're going to the doctor to get it checked. I'll be at school for part of the day, but I will miss English. I'll turn in my work before I go though." Foreshadowing.

"No problem, Anna. See you on Friday instead."<sup>12</sup>

Anna wasn't in class on Friday. The following week, all of Anna's teachers received word that a strange tumor had been found during Anna's hip x-rays and she was scheduled for a biopsy. I glossed over the email, still relatively unconcerned. We had only been in school for a couple of months, and I had already received countless messages from parents describing their children's medical ailments ranging from ADD, ADHD, and anxiety disorders to depression, migraines, and seizure activities. I was not necessarily desensitized, but definitely inundated. Increasingly, teaching in a bureaucratic system fraught with anxious parents had taught me to steer away from reactionary responses and wait to manage genuine issues. I prided myself on being calm and cool-headed. My mantra became "Be aware, but wait and see." This attitude kept me from joining the ranks of those passionately storming the administrative offices causelessly or reacting fitfully to an upset student or parent.

A week later, I received a five-sentence administrative email informing me that Anna's biopsy confirmed the presence of Ewing's Sarcoma and that her teachers should make every effort to support Anna's academic progress during this period of illness. I had no idea what to make of this diagnosis. I broke one of my cardinal rules as an academic and searched Wikipedia for some medical insight:

**Ewing's sarcoma** or **Ewing sarcoma** is a malignant small, round, blue cell tumor. It is a rare disease in which cancer cells are found in the bone or in soft tissue. The most common areas in which it occurs are the pelvis, the femur, the humerus, the ribs and clavicle (collar bone). Five-year survival for localized disease is 70% to 80% when treated with chemotherapy. Long term survival for metastatic disease can be less than 10%.<sup>13</sup>

Even though I would certainly *never* let my students conduct research on Wikipedia, I came to learn quickly that (a) Wikipedia was right on this topic

and (b) Wikipedia's brusque overview of the tumor and life expectancy is representative of the kind of medical discourse that patients and families encounter when first attempting to understand a dire diagnosis. As I sat staring at my computer screen, I was immediately aware that the scientific reality of the cancer doesn't care who it rattles with its sudden and unexpected appearances. Next, I learned that Ewing's Sarcoma is not staged like other cancers. However, as I dove further into the dark depths of the Internet, I found that oncologists would likely place Anna's disease at Stage Four. Stage Four. Stage Four means that the cancer had likely metastasized and spread throughout her young body. I responded to Anna's cancer diagnosis in a manner that was uncharacteristic—I did not plan my actions, I did not evaluate my role, I did not know what I was going to do; I just knew that I *needed* to do something.

**22 NOVEMBER 2010—10:30 A.M.**

Three years ago, I taught Anna's older sister, Patrice, in my Communication and English classes. She also competed for me on the Forensics team, and I've always liked her a great deal. While I kept up with Patrice casually about her college experiences, I hadn't really talked to her mother in a couple of years. I wanted to provide some sort of recognition of the five-sentence, impersonal email I received announcing her daughter's departure from her normal teenage life. I didn't want their devastating disclosure to be met with silence. I couldn't construct an adequate email because I didn't know what to say, so I picked up the phone and dialed, hoping that I would be able to fill the discursive silence with something comforting and remotely adequate.

"Hello Carol. This is Hailey Drescher, Anna's English teacher. I got the email regarding Anna's biopsy. I don't really know why I'm calling actually. I don't want to send home any work, and I'm not at all worried about her class progress. I guess I just wanted to call. . ." I was rambling. . . awkwardly rambling. . . I needed Carol to fill the silence that I feared would hang between us if I stopped talking. I continued, "I'm sorry. I guess I'm just worried about her and wanted her to know that I was thinking about her. We've missed her in class. Her absence hasn't gone unnoticed."

For a communication teacher who is often asked to speak at school functions and holds a reputation for being poised and articulate, I was crashing. She stopped me [thank God]: "Thank you Mrs. Drescher. Would you like to speak with Anna?"

"Oh, yeah. Yes, thank you. I would like to, if she's available?"

"Let me see if she's awake; she's been napping."

Although I spoke with Anna frequently in school settings, we never communicated outside of the classroom. Some students spend time in teachers' rooms before or after school, avoiding the complicated networks of high school interactions. Students would come to me with their questions about awkward social situations, peer pressure, homework, their parents' divorce, and other sundry concerns. Anna was not one of these students. She was popular, well-adjusted, had a solid group of friends, and she had a strong relationship with her parents that afforded her a safe place to seek answers about private matters.

For the next half-hour, I sat at my desk, where I typically graded adolescent prose and fixed syntax, and I talked to Anna on the phone. At first, our conversation was stilted:

"Hey Anna, it's Mrs. Drescher. We've missed you in class."

"Thank you, I'm going to try to come back next week. I'm also trying to keep up in *The Scarlet Letter*, so I'm not behind. My paper is done. I meant to send it with Sarah, but I forgot. I'm sorry, can I email it to you?" Anna was nothing if not conscientious.

"I'm really not concerned about your work or paper right now. Truly, don't worry about it. We'll get to it later. I saw the email. I guess the next step is some form of chemotherapy? I don't know much about this type of cancer at all. My mom was diagnosed with breast cancer while I was finishing college. She went through chemotherapy. . . . She said the ice cream was great." I dip back into my source of comfort, seeking identification in the face of uncertainty and distance.

"There's ice cream?"

"Oh yeah! Apparently they have some sort of magical freezer full of ice cream, and the nurses will bring it to you if you ask. I think my mom had popsicles. Now, I don't mind popsicles, but I prefer actual ice cream if there is a choice. I wonder if you can get one of those individual sized Blue Bell homemade vanilla ones. That would be good."

She was laughing, and I was starting to regain my terra firma.

"Huh, I'm not sure. We didn't really discuss the ice cream yet."

"Yeah, that makes sense; however, next time you talk to the doctors about the treatment plan, I would like to know what kind of ice cream selection process we're dealing with here. Also, according to all the television shows I've watched involving cancer, hospitals, or doctors, it seems that attractive male doctors abound. Has this been your experience so far?"

Again, laughter. Again, relief for me and a bit of normalcy amidst the flurry of uncertainty.

Anna affirmed my question, “I have only been a couple of times to the hospital so far, but there is one cute one. I think he is going to be one of my primary doctors. I’m not sure yet.”

“Excellent. I feel that both ice cream and attractive male doctors are crucial to the recovery process. Sorry, I know your diagnosis and my mom’s cancer are not the same, but I try to relate through experience. I think you will find that is how people instinctively attempt to show support and communicate. . .” [*God, stop teaching and just be yourself*] “. . . anyway. . . I digress. . . . My mom was allowed to have visitors in the room while she was receiving chemo. The process was several hours long, so it was nice to have people around. I went with her sometimes.” Overstatement. Okay, lie. I had never gone with my mother for chemo. I had been to multiple doctors’ appointments, I was there for her surgery, and I stayed in the Rotary House attached to M. D. Anderson, but I had never been there for chemo. I was finishing college in Indiana and had not been able to come back to Texas while she was having her treatments.

I lied to make Anna more comfortable, to make myself more comfortable. I *wanted* to have been in that room with my mom so that Anna would know that I meant what I said next: “I’ve been with her before and wouldn’t mind going with you if you like. Truly, I wouldn’t really be going for you. . . . I have some single friends and would like to see this attractive doctor you speak of. Also, I *really* like ice cream.”

“Thanks Mrs. Drescher. I would like that.”

The humor was unifying and her response was soothing.<sup>14</sup>

### EXPLAINING EUPHEMISMS

Teaching high school English to juniors requires explaining literary devices in ways that will resonate with students and that they will find applicable to their lives. Some devices are more challenging than others to put into context. Irony is a ridiculously difficult concept to teach. Alanis Morissette made it all the more arduous with her catchy, but utterly flawed 1996 song, “Ironic.” Frequently, when I introduced irony to my students, some would impulsively sing: “It’s like rain on your wedding day; it’s like a free ride when you’ve already paid . . .” No those things are not *ironic*; they are simply *unfortunate*. In the colloquial: “they suck.” Euphemism. Since explaining the term using sexual innuendos might be memorable, though inappropriate for my high school audience, I typically turned to the topic of death to help unpack this concept. With a room full of high schoolers, most of whom had not experienced death in personal terms, I would listen to their euphemisms:

“Passed away.”  
“Kicked the bucket.”  
“Lost.”  
“Perished.”  
“With God.”  
“Bought the farm.”  
“Met the Grim Reaper.”  
“Gone to meet their Maker.”  
“Pushing daisies.”  
“No longer with us.”  
“Resting in peace.”

My favorite example is from John Steinbeck's *The Grapes of Wrath*. When close to death, Grandma is described as “a-pawin’ for a shovel.” The novel was part of our junior reading curriculum, and the students found Steinbeck’s story of the Depression-era Dustbowl *riveting*. Hyperbole.

In the context of Anna’s illness, I realized that my teaching of euphemism had to change. As one of my students was slowly dying of a rare bone cancer, there was no way to maneuver around it delicately. My students all knew that their friend, their peer, was *dying* (not *passing away*, not *a-pawin’ for a shovel*, but *dying*). In teaching this content to my students, in reflecting about what it meant to use the concept of death euphemistically while one of my own students was, in fact, dying, I became acutely aware of how others were responding to Anna and her diagnosis. Bearing witness to others who are dying has a way of fueling our own anxieties about death, about facing our own mortality.<sup>15</sup> Perhaps given my relative youth, my naiveté, my belief in miracles, my experience of witnessing my own mother “beat cancer,” or simply my complete denial that the death of a child was actually possible (especially a child I knew and cared about), I never considered distancing myself from Anna. She had accepted my offer to attend her chemo treatments, effectively admitting me into her world of uncertainty, pain, and fear, and I never considered rescinding that offer. My first offer led to subsequent offers, a series of commitments, until the parameters of our relationship broadened and deepened. Surrounded by massive uncertainty, I found some relief in the few things I could control. I could control my commitment to Anna. I could be there until resolution, and I needed to be. Time with Anna was no longer something I *offered* to give, but that I *asked* to have. Time with Anna while she was dying was a gift that Anna, and her family, graciously extended to me.

I started visiting her in the hospital and later in her family’s home. Originally, I had volunteered to help keep her current on her schoolwork from the confines



of her hospital bed; while she received the invasive medicine through a port in her chest, we would discuss *The Grapes of Wrath*. She called me from the hospital and completed verbal examinations over the phone. She wrote papers on the plight of the Joad family while fighting through her own life-threatening journey. She made me promise I would remain unbiased in my grading, and she continued to turn in A-level work. She came to class draped in sweaters and hats to keep her warm, and ruefully mocked Holden Caulfield's jaded pessimism with the sort of introspection one might gain from facing grave realities. She rallied through rounds of chemotherapy, radiation, and English III with grace and strength.

By her senior year, I was no longer her English teacher. As she moved on to English IV and new teachers, the cancer continued to invade her body. My trips to the hospital became more frequent, and while my role in her life shifted from pedagogical to personal, I continued to cloak myself in the retreat of my "academic brain." Literature and research have always served an effective escape route for me.<sup>16</sup> As such, I ran headlong into the world of the classics, seeking what the gifted educator Parker J. Palmer describes as a "sociological imagination," comparing the experience to donning a pair of 3D glasses and seeing the world anew.<sup>17</sup> Similarly, I began to experience my place in the world with Anna in terms of literary devices—desperately seeking metaphors, subtext, euphemism, and humor. There, I wrapped my time with Anna in the world of elegant (and sometimes stumbling or even stark) prose, a fecund lexicon, waiting for the dénouement.

**10 MAY 2011—4:00 P.M.**

Today is Anna's 18th birthday. She was in the hospital again starting on Sunday night. I know it had to be a great deal of pain that forced her there on Mother's Day. They had plans to have a nice lunch and go to the Mavericks' game. She told me the pain and nausea were so intense that even her massage therapist couldn't relieve her of the back spasms. She tried to explain to me what the pain felt like, but she had no words. The hip pain is the worst; when it comes, she can't hold still even though it hurts to move. She explained that her back tightens and refuses to let go. The muscles constrict, release, and constrict again.

"Paroxysm" I mutter. It was on her junior vocabulary list, and she had underlined it in countless course texts as required. She nods.

This is a different type of pain, caused by her immobility—hours of doing nothing but lying in bed and sleeping. Anna hoped that moving, walking, and even just sitting would help to relieve the spasms, but the rest of her hurt too

badly to move. She knew the back pain wasn't the tumor because it ached *differently*. They began a new set of scans the following Monday, hoping to determine where to focus the new rounds of radiation. Everywhere they marked her body signaled a tumor site. She already knew most of them based on the locations of her intensifying pain. The rising bumps on her head indicated the cancer's presence well before the PET machine scanned her skull. Foreshadowing.<sup>18</sup> She intimated that it was unnerving to be able to pinpoint the locations of the growing tumors. Her growing knowledge of her own body, of her own pain, proved to be as insightful as any high-tech medical equipment or attractive doctors available.

Previously, when I had asked her to describe the pain, she proclaimed that she was a "90 year-old being pulled behind a freight train." We laughed, and I told her I liked her use of vivid imagery. I paused for a moment, caught up in how well playwright Margaret Edson's *Wit* was able to capture my own experience with observing cancer. Truly, there seemed no other way to battle this disease except through the use of wit. The nurses on Anna's rotation also employed this tactic aptly. Anna was on enough pain medication to "kill half the floor," one nurse had mused. Hyperbole. I asked Anna, "If the pain was transferred to me even briefly, what would happen?" "You would pass out on the ground," she replied laughing.

When the two of us were alone, a couple of nurses came to check on her portable toilet, commenting on the lack of "entries" in its bowl. Euphemism. Anna smiled politely and told them there was some in the bathroom. They remarked cheerfully about how great it was that she could "make a smudge," even if it wasn't much. I remember the look she gave me—apologetic and pure teenage angst. Perhaps more unimaginable than dying from cancer, she was a teenager, talking about her bowel movements in the presence of her English teacher; this couldn't be how she envisioned her life. Understatement. Rolling her eyes, she asked, "Isn't this great conversation?"

Wanting to offer comfort through some sort of common experience, I told her about giving birth to my son, Bryce. I shared how the nurses assured me I was pushing correctly because I had "pooped a little." Anecdote. I had told almost no one that story and had mostly blocked it from my own memory. But in that moment, I needed Anna to know that I could empathize with her embarrassment and feelings that she had lost all expectations of privacy. I was mortified when I had lost this sense of bodily integrity during childbirth; and suddenly it seemed so small and insignificant. Many things seemed small. I was wearing fresh lenses and seeing things anew. Anna shared her own shift in perspective, recalling that

she was once worried about having her wisdom teeth removed because it was considered to be a surgery. She recalled being terrified when she first saw a face-mask that some radiation patients had to wear to hold their heads securely to the table. These anxieties had now been dwarfed by bigger fears and by elevated levels of courage as she encountered more procedures, treatments, and precautions.

#### THAT WHICH DOES NOT KILL US?

Anna continued taking the radiation in stride. The poking, prodding, and sticking she tolerated, but she drew the line at the take-home mobile pain pump. The amount of medication that it took to keep her pain at bay could no longer be administered orally. Instead, in the hospital, it was pumped into her veins continually, through a port in her chest, with a relief button illuminating every six minutes. The emerald flash brightened, and she would instinctively hit her button and wait for the brief wash of relief. To me, it was reminiscent of the green light at the end of Jay Gatsby's dock: a symbol of his dream and hope for the future. F. Scott Fitzgerald's *A Great Gatsby* is my second favorite text to teach (next to *The Catcher in the Rye*); it is full of beautiful language and stocked with symbolism. In making this connection, I would try not to think of Gatsby's death—floating in the water of his symbolic rebirth.

“What is it about the pump that you are opposed to?” I asked, returning to Anna's pain. I reminded her that last time I saw her in the hospital, she was afraid to go home. She feared the pain would peak and she knew from experience that it could take them hours to bring the agony under control. Hesitantly, I recounted this experience: Anna writhed in a dimly lit room while an older medical fellow leaned over her, inquiring about levels, doses, and hours in a hushed whisper. The physician left briskly and informed Anna's Aunt Cathy that she would have to increase the narcotic dose. I stepped outside, feeling like an invasion of Anna's privacy, of her mother, Carol's, space, of their family.<sup>19</sup> Would I be seen as intrusive? What were the boundaries of this undefined and nebulous relationship? Could I be there? (*Please let me be there.*) It was my own fear that led me to rush hurriedly from my classroom to the hospital on that Thursday. I worried that Anna would fall into a narcotic-induced coma and that I would *miss her*. Double entendre. I feared that this cancer would swallow her and she would not resurface. Metaphor. Anna had resurfaced last time and she did return to her pain.

When I reminded Anna of all of this, she acquiesced slightly. Perhaps she'd take the pump, she conceded. She used medical terms related to the annoyance of unplugging herself to go out and then re-engaging when she returned home.

They are terms I can no longer remember, and terms that I wish she had no cause to know. This was a frequent feeling for me. She ordered medicines by name the same way I ordered my non-fat chai latte at Starbucks. She knew which pairings were safe for her to consume, and which couldn't be taken in tandem. She is seventeen. . . . She *was* seventeen. Her friends spoke in acronyms and debated issues related to "Prama" (Prom juxtaposed with Drama). Again, I listed the positives associated with the pain pump while listening to her concerns. We discussed the pros and cons about relying on this device:

"But there are a limited amount of steps left to take, and I don't want to take them too quickly." Anna's clear and compelling counter-argument.

I was uncertain how to navigate this perilous territory. She wasn't my child, my sister, or even my peer. Our relationship was not conventional or easily defined, and I worried about crossing hidden boundaries. I was *just* a teacher, and I had strayed dangerously far from my expert text. Again, I questioned my role and struggled in navigating the dialectical tension between offering support and privacy. I disappeared into the safety of metaphor: "I don't know the length of the staircase, and I understand the fear of catapulting down the steps at a break-neck speed, but there are some steps that have to be taken to improve the quality of life. The pump is a necessary step. It will ease your pain; it will make you comfortable enough to visit with your friends and family; it will provide peace of mind; it means less visits to the hospital." Restatement of thesis.

The pump, as we all feared, offered far too little relief and we continued to hurl forward. Metaphor. The introduction of a Hospice worker into her home also added a difficult element to accept in her life—a stranger in her house, regulating her medication, providing comfort from the position of official outsider. Anna seemed less concerned with this addition because she knew that Hospice could provide support for her mom. Anna frequently considered her mother's position when thinking of her own. Although I was uncomfortable with the symbolism associated with Hospice's arrival,<sup>20</sup> Anna's family deserved this support and Hospice's services would ultimately benefit Anna tremendously.

## WRITING OUR LIVES

Anna told me that she had been trying to journal. She wanted to document her journey. She wanted a record that could perhaps aid and bring peace to others. "Like the little boy who wrote the poetry when he was dying. What was his name Mrs. Drescher?" I knew immediately that she was talking about Mattie Stepanek, the young poet and peace activist who chronicled his experiences with Dysautonomic Mitochondrial Myopathy. "Mattie Stepanek? He was wonderful,

I saw him on *Oprah* before he died.” As I uttered these words, I realized that Anna was hoping to leave a legacy that would live on beyond her death. In the wake of Mattie Stepanek’s death, his family and friends generated an enormous movement aimed at helping children and adults advocate for peace through more play in the world (a mission Mattie himself began before he died); I wondered how Anna envisioned her own life’s mission. . . . I wondered why any girl her age should have to consider her life’s mission.

I gave her a leather journal that I had saved, but never written in—a token of instrumental support. I bought it after watching the movie *Cruel Intentions* and coveting Sebastian’s journal. I had held onto this leather-encased tome for many years, this blank and beautiful book, because nothing ever seemed worthy enough to fill its pages. I briefly debated whether to give it to Anna—was it cheesy? Would I wish I had the journal later? What if something important did happen in my life and I needed it?—And then I realized that I needed it then; *I needed Anna to need it.*

“I think I’m doing it wrong. The words I write aren’t coming out correctly. What if I’m not representing myself in the way that I want?” Anna reminded me that she still needed guidance and assurance. I assured her that there was no wrong way to write in a stream of consciousness. I began to draw a comparison to Holden Caulfield in *The Catcher in the Rye*, but then remembered that she did not read the entire novel with the rest of her peers. So much changes and stays the same. Where *do* the ducks go when the pond freezes over?

Since Anna had begun talking about her journal, in the context of another teen who died before his story was finished, I began to get nervous and my hands were sweating. I feared Anna might want to discuss some of her feelings, talk about the *telos* of her treatment and her fears of what lies ahead. Unsure of how to open the door, or if even it should be opened, I recalled some of the academic texts I had consumed voraciously about the importance of speaking about death with those who are dying (especially adolescents), of not shying away from the reality of death, of helping to empower those who are dying with demystifying information.<sup>21</sup> I prayed that I was reading the words of actual experts and that I was equipped to speak to the needs of this very special child.

I began to crack open the door:

“I’m not trying to be macabre. . .” (confusion from Anna) “Do you know what macabre means?”

Anna giggled, reminding me that she was quite accustomed to me using words for which she had no definition. If we were in the classroom, she would write the word down and look it up later.

“Macabre. . . um. . . dark. . . sullen. . . gloomy. . . . So, I’m not trying to be macabre, but. . .” I asked Anna gently, slowly, and carefully: “Do you still want the same thing to be done with the journal if. . .” I trailed off, hoping she could read my mind and not force me to finish my sentence. She looked confused and I tried again: “Do you still want people to read it if. . .”

Anna stopped me: “Yes.”

I breathed in and asked, “Who do you want to read it?”

Anna answered freely, “My family and close friends, the ones in the journal. The people I’m close to.”

“Got it.” I tried again to discuss openly the path of her illness by descending into euphemism, a tool I usually dislike. “Anna, if and when. . .” I couldn’t say *die*, it wouldn’t come; as if avoiding the word could avoid the reality of her impending death. I didn’t want to have *this* conversation. I worried it was not my place, that I would upset her parents, Carol and David. I wondered if it was too soon to start *this* talk. Was she ready? Does she need to talk about this? Rhetorical questioning. I usually consider it too tawdry to employ. But, I felt that Anna had opened this door and needed this (perhaps it was me who needed this?).

“If and when. . . is there anything else you know you want?” (Again, confusion.) “For instance,” I continued, “there is a song I know I want played. There are things I know my parents want, and there is nothing impending for me. There are just things we know we want to have done, in case. If there are things like that, it would be okay to write them down in the journal. It would also be okay to tell me if you want to. It would be okay to tell someone.”

I looked for a reaction. There was nothing. I began to doubt all of that expert scholarship. I kept talking to Anna, trying to communicate what I thought to be important: “This is a tenuous line Anna. I don’t want you entering that headspace. I don’t want you obsessing over it, or even spending time thinking about it, but if you think of something. . . the future is unknown for all of us. You should write about how you want to be a therapist who works with people with drug addictions. You should write about the concerts you want to go to. *You should not limit yourself*. I could potentially be hit by a truck on my way home from the hospital today, and I know *I* feel better having others know what I would want if that were to happen.”

She seemed to comprehend. We talked about what a difference a year can make. Cliché. I reminded her that a little over a year ago, I had lost twins during pregnancy. In the aftermath, I doubted I would be able to carry a baby ever again. When it happened, Anna was one of the few people I told. She empathized with

pain and lost dreams. Then, almost exactly a year ago, I found out I was pregnant with Bryce. She laughed. “You never would have thought you would have a baby, be retiring from teaching, and becoming a stay-at-home mom.”

I agreed, “You never know.”

I’ve allowed the plane to dip into a death dive, and I’m back to the ascent. I pull up on the lever. Metaphor. “Write about it all, and don’t be afraid to write about the future, *your future*.”

Our discussion wandered into her future, considering what gaps must be filled. We talked about her radiation mask, and I compared it to Hannibal Lecter’s. Allusion. She’d never seen *The Silence of the Lambs*—I balked. She considered herself to be a horror movie connoisseur, and this was a serious hole in her education. Anna asked to see *Water for Elephants* with me since we had talked about the book frequently. I promised I’d wait for her, silently wondering if I’d ever see it. She had also never been to Red Lobster, a revelation I found to be ridiculous. I explained to her that those cheesy biscuits are a necessary life experience. Her family was planning to take her to Kobe Steak for her birthday dinner. Kobe is one of my favorite birthday locations as well. Another similarity? Was I just searching for similarities, trying to justify our closeness, our ease with one another, the aching conversations we continually had. Critical analysis.

With the transition into birthday talk, I reached for her present. Shopping for her was difficult. Understatement. It was paralyzing. She loved clothes, but her size was difficult to determine and it took all of her strength to try on a couple of shirts. I loathed the symbolism associated with purchasing a trendy house-key cover, buying a purse that her narcotic pump could fit inside, or selecting a pillow stitched with the phrase “Life is Good.” None of these options were fitting. I settled for two different shades of purple (her favorite color) nail polish, sassy nail clippers, and a purple-blue pashmina scarf. I thought the scarf could serve dual purposes—it was decidedly fashionable, and she was frequently cold.

Next, the card—I realized quickly that Hallmark had not anticipated this particular exigency.

“Birthdays are good. . . it means you lived another year.” I put it back quickly. Subtext screamed at me from the rack.

“Now is the time for wine and sweet words.” Yes. Fine.

I was crying as I approached the clerk and the woman behind the counter was clearly uncomfortable with my emotional display. I considered telling her, “I’m buying a birthday present for a girl who will probably never turn 19, and I was struggling to find a card.” Instead, I remained silent, certain my explanation would only increase the awkwardness. I returned to my car and attempted to

write a message in the card. Who knew when the right time was to express all the sappy sentiments I had stored? About a month before her birthday, Anna told me that visitors had begun reminiscing about her childhood, and it made her feel as though they were already saying goodbye.

“I can’t keep having these conversations,” she told me.

I abandoned my heartfelt message and chose what I hoped would serve as therapeutic humor. Not only does humor have the power to persuade a high school sophomore to wear his tie correctly, but it can also aid in healing and coping with life’s most traumatic situations. Using the only treatment I was licensed to provide, I wrote about an unlikely combination of clown school, bass fishing, Shetland ponies, and lime/grape slushies. Escapism—a common theme in literature. I slid the card into the purple bag and headed to the hospital.

She loved the presents and asked me to tie the scarf around her neck in a “cool knot” (she mistakenly thought that I had a purchase on coolness). We continued talking about the possibilities of owning a Shetland pony (free rides, buying carrots in bulk, working at carnivals) when she became physically uncomfortable. This was the first time I had seen even a glint of frustration or anger from this girl who faced truly frustrating and anger-inducing afflictions. The wrappings from the present were scattered on her bed: tissue paper, polish, clippers, she was wrapped in this new purple pashmina, and the pain caused her to feel claustrophobic and hot. She suddenly needed everything off of her. Similar to a panic attack, her reaction was sudden and adamant. I was sitting on the foot of her bed and had just commented on the amount of comfort an eggshell mattress adds. I jumped to remove the tissue paper and bag while Carol deftly grabbed the rest; the purple cloth was stripped from her neck as quickly as it was placed there. And almost immediately, the anxiety ebbed as Anna hit her green light, and eased back down into the bed.

On the drive home, I called our school nurse. I was worried that I had pushed Anna too far, and that she wasn’t ready to consider what might be impending. I was told that one of my students’ dad had died suddenly over the weekend. This man worked out, he ran, and he kept himself healthy. He was a smart man, a psychiatrist, and he had a heart attack in his car. His family had decided to remove him from his ventilator that morning. This conversation reminded me that there is no certainty—no comfort of poetic justice, no certain dénouement.

**6 JUNE 2011—8:00 P.M.**

I visited Anna this evening at home. Hospice had made her as comfortable as possible, and she was lying in her parents’ bed. I made my way into the room,



kicked off my flip-flops, and crawled into bed next to her. I put my head on the pillow adjacent to hers and began reading. I had brought Todd Burpo and Lynn Vincent's *Heaven Is for Real*, as she requested. Her eyes were closed, and I wasn't sure that she could hear me, but I lay there and read aloud for an hour. I skipped some places in the novel, wanting to get to the best parts. I forbade this reading tactic in my classes; however I didn't have time for exposition and character building—I wanted Anna to see this little boy's heaven. I wanted her to hear about the "markers" on Jesus's hands. I wanted to give her (and myself) peace. After an hour, my voice was growing hoarse, and her peaceful breathing made me think she was asleep. I closed the book, listening to the hum of her oxygen machine.

"Thank you." Anna whispered. She had been awake. "Is it okay if I keep my eyes closed while we talk? I don't want to be rude."

"Of course Anna." Pause. "I'm leaving for London on Wednesday."

I was preparing to take Anna's Shakespeare class on an eight-day trip to London. It was a trip she would have originally attended.

"I know Mrs. Drescher. It really scares me."

"Why does it scare you?"

"I'm just not sure if I am. . . . The future is very uncertain." Again euphemism. Her voice was weak and breathy.

"I know Anna. It scares me too. Do you think you can wait on me? It's eight days."

"I'm not sure."

I was crying. I had never lost control in front of her. Thankful that her eyes were closed, I continued, "If you can't, it's okay. You can go Anna. If you need to, it's okay. You don't have to wait for me." No literary device, just pain ripping through me.

"Okay."

I tried to continue apologetically, "I'm sorry. I know you don't like it when people say goodbye. I know it is premature."

"It's okay. A lot of people have been saying goodbye recently." She laughed lightly, and I was grateful. Relief humor unified us, and we laughed together.<sup>22</sup>

Laughing, I responded, "I'm leaving for eight days. That's why I'm saying goodbye! What's their excuse?"

"You're right, Mrs. Drescher, I don't know."

We laughed again. I had given Anna my permission to die. Facades razed, I inquired, "Anna, what scares you the most?"

She asked wistfully, "What is it going to be like when it comes?"

No literature offered the answer here, but I suggested, “I hope it will be peaceful, and you just drift off in your sleep. That’s what I would want.”

Anna agreed, “Yeah, that would be good.”

I’m not sure how the conversation changed. I think she tried to move and couldn’t. She was lying flat in the bed and could barely move her hands. They had begun to constrict due to malnutrition and pain, and she could not straighten them. I asked her, “Is the pain still a 90-year-old woman being dragged behind a train?”

Smiling a bit, she responded, “No, it’s worse now.”

“How would you describe it now?”

“Screaming.”

“Screaming? Does it hurt in the bones?”

“Not really the bones—just screaming. Everywhere.”

“If it was a color, what color would it be?”

“Red.”

“Red?”

Anna thought about this more and refined her answer: “Hmmm. No. Deep purple, but an angry purple. Deep purple with flashes of red.”

“Okay, I like this game. Nice imagery and use of symbolism. If it were an animal, what would it be?”

“Well, I don’t want to say something generic like a lion or tiger. What about a warthog? Ohhh, or a wild boar? Those are really mean and destructive. They destroy crops and attack humans.”

“Wild boar sounds good. I think you got it.”

“Maybe one with three snake heads,” Anna continued.

We talked some more. The pain was persistent, and the medication so strong that it was causing hallucinations. I asked if she felt like the woman in Charlotte Perkins-Gilman’s *The Yellow Wallpaper*. Literary allusion.

“Oh goodness, I really hope you don’t find me creeping around the room on the floor,” Anna laughed. She then asked, “Mrs. Drescher, is someone snoring?”

“No, Anna, that’s just the oxygen machine.”

Never losing her sense of humor, Anna responded: “Oh, I thought it was strange that someone was sleeping and snoring on the bathroom floor.”

I had been there for almost two hours, and she was weakening. The slushie I had brought her had melted into a viscous mess, and its original colors were no longer distinguishable as lime and grape. Slushies at our meetings was nothing more than tradition; she had barely been able to eat or drink for three days by

this point. A month prior, she had developed what she referred to laughingly as “the drops.” Her hands had grown weak and cramped, and made it almost impossible for her to hold anything with weight.

I knew I needed to leave. There were a finite number of hours with Anna left, and her family had already generously given several of them to me. Just a few more minutes.

“I have a couple of things I’d like to ask your permission for Anna.”

In the month prior, I had been harassing her with a barrage of questions in preparation for her high school graduation. As her teacher, and more recently, her friend, I had transitioned into the liaison between the school and her family. It was a semi-professional role that I was comfortable in. However, these questions were more personal. I was shaking. I knew that by asking these questions, I had given in to her death. These questions were symbolic, they contained subtext, and their connotation spoke to my fear and terror of losing Anna. In my heart, I feared. . . I knew. . . she would not see me back from London.

“If I should have any more children, and should it be a girl, I would like to name her Anna Myren Drescher. Would that be alright?”

“Really? Yes. Yes, I would love for you to name her that.”

“Thank you. Also, you had mentioned wanting to write your story, similar to Mattie Stepanek’s poetry. I know you’ve written a little in the journal, but do you want me to try? Do you want me to try to do it for you?”

“Yes. Of course. Please try.”

“Okay, I’ll do my best. I’ll try. I don’t say this frequently or to many people, but I love you.”

“I love you too,” Anna responded with exhaustion and a slight smile.

I had hit my bottom. I had said all I needed to say. I would have no regrets.

“Okay, I’m going to go and let you sleep. I’m going to come back tomorrow, and we can watch *The Silence of the Lambs* like we’ve been talking about. I still can’t believe you haven’t seen that, what a freaking tragedy and gap in your education.”

“Okay Mrs. Drescher, see you tomorrow.”

I hugged her gently and kissed her cheek before closing the door behind me.

Anna’s pain surged out of control at 4:30 a.m., and she had to be medicated into a coma. The medicine allowed her body to finally release, and she was able to lengthen her legs, arms, and fingers. Her mother later told me that she seemed truly at peace for the first time in months. Anna died a day later while I sat in the Atlanta airport with twelve of her classmates waiting for our flight to London.

When I returned, I found that Anna had left an entry addressed to me in her journal:

*Mrs. Drescher,  
I want to be there when Bryce says his first sentences and starts using his words the way you taught me to use mine. No, you did not teach me how to speak English, but you gave me my confidence to speak my mind and advocate for myself and rationalize whatever thought I was having. The more I shared and opened up with you, the more I felt I could do it with others. So thank you for that, and know I am watching as Bryce sails through the rudimentary\* stages of speaking for himself.*

She had underlined her vocabulary word.

We do not live through our experiences in order to simply interpret and write about them.<sup>23</sup> Instead, our writing comes secondary as a means of making sense of the existential crises that change the trajectories of life,<sup>24</sup> as we strive to “show life’s complexity and fragility in depth and detail.”<sup>25</sup> We found writing this essay to be evocative. In many ways, writing this essay provided an opportunity to “purge” some ghosts that suggest we did not “do enough,” that death could somehow be prevented, despite all of the best medical and individual interventions. As Arthur P. Bochner reminds us, we must continue to be attentive to the “effects that linger—recollections, memories, images, feelings—long after a crucial incident is supposedly finished.”<sup>26</sup> Of course, the communicative experiences we have in day-to-day life, especially as we try to form meaning through reflexive recollection on past experiences of grief and suffering, are “not always rational, and often messy.”<sup>27</sup>

Anna’s parents remain active in my life and I in theirs. Their support of my personal and professional endeavors is unwavering. Goodall speaks to the challenges for ethnographers in delineating ethical questions of “ownership” when it comes to stories that involve other people.<sup>28</sup> With the deepest of respect for Anna’s family, I sought their blessing to share our experience—my attempts to assign meaning to their daughter’s death and to tell the story of my relationship with Anna. They consented immediately before I ever began writing this project, and again after reading this account. We are incredibly grateful for the role of Anna’s parents in supporting this telling of Anna’s story so fully.

In reflecting upon my own motives for writing my narrative with Anna, I find that they are twofold. I write in an attempt to make sense of my unexpected and enduring relationship with Anna. More significantly, I write to

fulfill my promise to Anna and to give permanence to a life beyond the scope of those individuals fortunate enough to have been impacted directly by Anna's life and death. In this way, by combining my scholarly training in autoethnography and performative writing with my deeply intimate experiences with life and dying (experiences that, for most people, occur when we have little, if any, prior training), I hope to offer at least one heuristic for others who will inevitably face loss, death, and grief. Mirroring the complex reality of lived experiences, my accounting of Anna's life and my placement in her life are neither complete nor perfect. I have taken great care to present our narrative honestly, but like most of life's most meaningful relationships, my relationship with Anna's family cannot be categorized cleanly, my role in Anna's life and death cannot be defined neatly, and the impact Anna had on mine has not yet been (and maybe never will be) resolved. Death, like life, is messy.

Norman K. Denzin notes that "bringing the past into the autobiographical present" means we insert ourselves into the past and "create the conditions for rewriting and hence re-experiencing it."<sup>29</sup> This act of bringing the past into the present has generated many stark realizations about the legacy of hope and lightness that Anna left in her death; it has also generated the sort of pain that comes with making present moments from our pasts that have most caused us grief. Similar to Ruth Behar's analysis of bringing emotion into conversation with anthropology, we have found this project to dance in an "intermediate space we can't quite define yet, a border between passion and intellect, analysis and subjectivity, ethnography and autobiography, art and life."<sup>30</sup>

I do not teach high school anymore. I stayed home with my son, Bryce, for his first couple of years while I began graduate school. I also work for the foundation I helped create with Anna's parents as a legacy to Anna—1 Million 4 Anna.<sup>31</sup> What started as an online effort to coordinate one million simultaneous prayers for Anna has evolved into an organization committed to raising money to end Ewing's Sarcoma and support children afflicted with this disease. Giving up my classroom to another teacher was not difficult; the hallways were full of strangers. Anna's class graduated the year she died, and the juniors I last taught have gone to college. Again, it feels like the end of a classic novel. Huck Finn alights for the West, the Joads are dispersed, Gatsby floats lifeless in his pool, and Lieutenant Frederic Henry walks home in the rain. ■

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## NOTES

1. H. L. Goodall Jr., "Narrative Ethnography as Applied Communication Research," *Journal of Applied Communication Research* 32, no. 3 (2004): 187.
2. Mattie J. T. Stepanek, *Reflections of a Peacemaker: A Portrait through Heartsongs*, ed. Jennifer Smith Stepanek (Kansas City, MO: Andrews McMeel Universal, 2005), 205.
3. The Mattie J. T. Stepanek Foundation, "Who We Are," *Mattie Online*, 9 March 2012, accessed 16 November 2014.
4. Norman K. Denzin, *Embodied Practices: Feminist Perspectives on the Body* (Thousand Oaks, CA: Sage, 1997), xv.
5. See Dwight Conquergood, "Rethinking Ethnography: Towards a Critical Cultural Politics," *Communication Monographs* 58.2 (1991): 179–94; Carolyn Ellis and Arthur P. Bochner, eds., *Composing Ethnography: Alternative Forms of Qualitative Writing* (Walnut Creek, CA: Alta Mira Press, 1996); Laurel Richardson, "The Consequences of Poetic Representation: Writing the Other, Rewriting the Self," in *Investigating Subjectivity: Research on Lived Experience*, ed. Carolyn Ellis and Michael G. Flaherty (Thousand Oaks, CA: Sage, 1992), 125–37.
6. Goodall, "Narrative Ethnography," 188.
7. Norman K. Denzin and Yvonna S. Lincoln, eds., "Introduction: The Discipline and Practice of Qualitative Research," in *The Sage Handbook of Qualitative Research*, 4th ed. (Thousand Oaks, CA: Sage, 2011), 1–19.
8. Tasha R. Rennels and Blake A. Paxton, "Sudden Death, Sudden Friend: Exploring the Role of Friendship in Continuing Bonds with the Deceased," *Qualitative Communication Research* 2, no. 2 (2013): 182–212.
9. *Ibid.*, 206.
10. Goodall, "Narrative Ethnography," 188.
11. John C. Meyer describes the use of the "relief theory of humor" as a means of reducing stress and tension by bringing levity to the situation ("Humor as a Double-edged Sword: Four Functions of Humor in Communications," *Communication Theory* 10, no. 3 [2000]: 310–31). Accordingly, joking while in the midst of difficult circumstances has the potential to unify, rather than divide. Kenneth Burke touts a similar utility of humor to make situations seem manageable, to dwarf that which seems magnified, and to recognize human foibles in the midst of grave uncertainty (*Permanence and Change* [Berkeley: University of California Press, 1984]).
12. In writing this piece, we have relied on Lorraine Hedtke and John Winslade's explanation of *remembering* as being more than simply reminiscing about past

experiences. Rather, remembering might be better considered re-remembering, as a “creative process that develops the life narrative of the living through a process of interaction with the dead” (*Re-remembering Lives: Conversations with the Dying and the Bereaved* [Amityville, NY: Baywood, 2004], 9). Using the metaphor of *membership* to signify the intimate group of family and friends who most significantly affect our own identity construction, Hedtke and Winslade maintain that we remember conversations as “deliberate acts of membership construction” to help maintain a loved one’s presence actively involved in our “club of life” (10). This dialogical mode of thinking suggests an act of active and ongoing engagement, of keeping alive not just the memories of someone who has died, but of maintaining the centrality of that person’s influence on our own identity.

13. “Ewing’s Sarcoma,” *Wikipedia*, The Wikimedia Foundation, n.d., accessed 10 June 2014.

14. Goodall suggests that even in the midst of dying, “laughter can transform the gray everydayness of ordinary life into something special, something memorable, something we tell others. (“Round Seven: Red Alert-Laughter in the Room and I Feel Fine,” *The Daily Narrative*, 14 September 2011, accessed 10 June 2014). Knowing that “managing cancer” is more than coordinating treatments and diminishing pain, we ought not ignore the therapeutic nature of humor, especially in the face of impending death. Goodall offered the world a great gift as he narrated his experiences with the cancer that ultimately took his life in August 2012. Journaling his adventures through “Cancerland,” Goodall used his blog, *The Daily Narrative*, to reinforce frequently the importance of humor, to stress the medicinal value of laughter. Goodall’s insights echo our own experiences, both in supporting loved ones who are dying and in our pedagogy with students.

15. In fact, friends and family of people with terminal diagnoses often seek refuge from their own feelings of discomfort and forced confrontation with mortality by widening the boundaries between the afflicted and themselves. In the exact moments in life when we are most likely to need the most support from our friends and family, our friends and family are most likely to fear our mortality as *contagious*. See Roxane Cohen Silver, Camille B. Wortman, and Christine Crofton, “The Role of Coping in Support Provision: The Self-presentational Dilemma of Victims of Life Crises,” in *Social Support: An Interactional View*, ed. Barbara R. Sarason, Irwin G. Sarason, and Gregory R. Pierce (New York: John Wiley, 1990), 397–426.

16. Retreating to the comfort of literature and scholarly critique is not unique to this story. Roger C. Bone, a prominent physician and educator, enveloped himself in this same sort of cocoon while dying from cancer (“As I Was Dying: An Examination of Classic Literature and Dying,” *Annals of Internal Medicine* 124, no. 12 [1996]: 1093).

17. Parker J. Palmer, *The Courage to Teach: Exploring the Inner Landscape of a Teacher’s Life* (San Francisco: John Wiley & Sons, 1998).

18. Mark Bernstein, et al. accurately warn: “tumor growth eventually leads to a visible or palpable swelling of the affected site” (“Ewing’s Sarcoma Family of Tumors: Current Management,” *The Oncologist* 11, no. 5 [2006]: 504).

19. For a description of the common reluctance to offer social support for fear of potential relational conflict and the concern that the provider may be seen as intrusive,

see Terrance L. Albrecht and Mara B. Adelman, eds., "Dilemmas of Supportive Communication," in *Communicating Social Support* (Newbury Park, CA: Sage, 1987), 240–54.

20. "Hospices are in a perfect position to routinely educate caregivers on the influence of psychological, social, and spiritual factors on pain and the myths of pain management in an effort to ease caregiver anxiety and fear, and promote adherence to medication regimens" (Debra Parker Oliver, Elaine Wittenberg-Lyles, George Demiris, Karla Washington, Davina Porock, and Michele Day, "Barriers to Pain Management: Caregiver Perceptions and Pain Talk by Hospice Interdisciplinary Teams," *Journal of Pain Symptom Management* 36, no. 4 [2008]: 381). My scholarly knowledge of the incredible merit of Hospice care to provide the most compassionate and competent care for Anna did not diminish the signifying power of the word "Hospice" in my imagination.

21. For an explanation of the importance of communicating openly with dying adolescents, see Estela A. Beale, Walter F. Balle, and Joann Aaron, "Silence is Not Golden: Communicating with Children Dying From Cancer," *Journal of Clinical Oncology* 23, no. 15 (2004): 3630.

22. Like Sheena Malhotra, we are "fascinated by the courage of humor and irony, catching again a shimmer of the exquisite human ability to simultaneously hold both the sad and the silly" ("Engaging Power Feminism through My Dance with Cancer," *Women's Studies in Communication* 32, no. 1 [2009]: 122).

23. Norman K. Denzin, *Interpretive Biography* (Newbury Park, CA: Sage, 1989).

24. Arthur P. Bochner and Carolyn Ellis, "Personal Narrative as a Social Approach to Interpersonal Communication," *Communication Theory* 2, no. 2 (1992): 165–72.

25. Lisa M. Tillmann, "Autoethnography, Communication, and Applied Research," *Journal of Applied Communication Research* 37, no. 1 (2009): 95.

26. Arthur P. Bochner, "The Functions of Human Communication in Interpersonal Bonding," in *Handbook of Rhetorical and Communication Theory*, ed. Carroll C. Arnold and John W. Bowers (Boston: Allyn and Bacon, 1984), 595.

27. Goodall, "Narrative Ethnography," 188.

28. H. L. (Bud) Goodall Jr., *Writing the New Ethnography* (Lanham, MD: Rowman & Littlefield, 2000).

29. Norman K. Denzin, "Pedagogy, Performance, and Autoethnography," *Text and Performance Quarterly* 26, no. 4 (2006): 334.

30. Ruth Behar, *The Vulnerable Observer: Anthropology that Breaks Your Heart* (Boston: Beacon, 1996), 174.

31. "Home," *1 Million 4 Anna Foundation*, 2013, accessed 17 August 2015, <https://www.1million4anna.org>.