

# HONORING OUR DEAD BY BREAKING SILENCE: REMEMBERING THOSE WHO DIED FROM AIDS

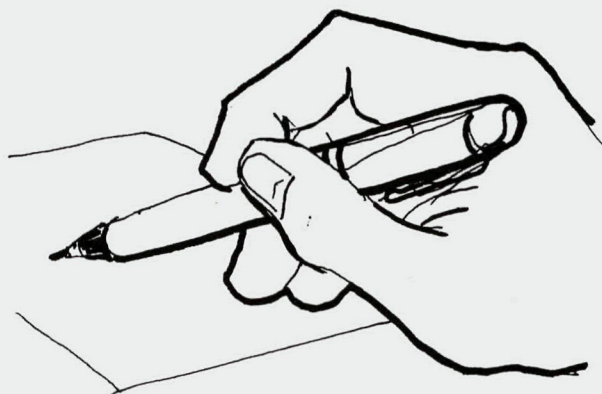
By **Cynthia Cannon Poindexter, Ph.D.**, Assistant Professor, Boston University School of Social Work

*Reading about what Elie Wiesel witnessed during the Holocaust triggers in the author a flood of memories about people in her life who had died from AIDS. In this memorial to them, she strives to articulate how their lives impacted her own, professionally and personally.*

## THE TRIGGER

In August 1999 I was reading a book about the writings and impact of Professor Elie Wiesel<sup>1</sup> when I began to feel flooded with unwelcome memories, and to feel a crushing weight of personal grief. Elie Wiesel is, of course, a Jewish man who was liberated at the age of 16 from a Nazi concentration camp, and who has spent five decades keeping the Holocaust in front of us in the hope that this unique historical event is neither forgotten nor repeated. My family and I were not connected to those events, and I will therefore never be able to understand the experiences of those who were. How, then, could reading about the philosophy and mission of this Holocaust survivor overwhelm me with a sense of mourning? Although I was feeling great sadness for Mr. Wiesel, as well as for all those who were victimized, I was feeling something that was more personal as well, which was not related to the Holocaust.

I am a social worker in the HIV field. The memories that flooded me were all of people I had known who had died from AIDS. These flashbacks were all connected with getting a call that someone was dying; being in a hospital room with a seriously ill person; saying goodbye to people I cared about and respected. I wondered where these incidents, which were from six to twelve years old, were coming from, and why they were so vibrant to me now. I began to write them down, a few each evening, feeling frantic and compelled to get them out of my head, off my heart, and into the computer, where (I hoped) they would



no longer burden me so much. For several days I felt raw with grief. I told my closest friends simply that I had been reading about the Holocaust, and that I was writing about people who had died from AIDS; but I didn't feel able to say anything more specific to them about why I was emotionally overwhelmed.

I have struggled mightily with whether or not I should share these remembered stories and the trigger for them, and I still am not sure of the wisdom of doing so. I fear that by externalizing these memories I will seem to be self-absorbed, self-indulgent, melodramatic, unprofessional, or unnecessarily self-disclosing. I feel vulnerable about exposing my feelings and foibles. I am also afraid that I will not be able to communicate the power of these moments. The worst fear I have about disclosing the trigger for these memories is that someone who survived a concentration camp or whose family was murdered in one will think that I am equating that experience to the HIV epidemic. I am not comparing these two ongoing terrible situations in the

least. HIV is an epidemic that is unprecedented in my lifetime for its devastation and social ostracism, but it is *not* purposeful genocide. I do not mean to draw parallels between the Holocaust and the HIV epidemic; what I do mean to say is that reading about Professor Wiesel's ideas of storytelling as a way of honoring the dead precipitated for me some grief and some long hidden stories of my own.

Perhaps if I highlight some of the messages from this book about Professor Wiesel, quoting and paraphrasing the author, Robert McAfee Brown, it will help to explain the context and illuminate somewhat my response. Brown states that Wiesel's goal is to be a storyteller, a witness, a messenger, a testifier, and a transmitter of memory for those who can no longer speak for themselves. He says that Wiesel was silent for a decade after his release from the concentration camp because it was impossible to speak about the horror, and then began writing because it was impossible not to speak about it. Wiesel came to see silence as a betrayal of experience. Brown also says that narratives of memory should not be analyzed, classified, codified, and interpreted. Rather, tales should simply be heard, repeated, and responded to by telling other stories. Brown says that Wiesel's underlying hope is that memory is an antidote to indifference.

As I read this biography, I was particularly affected by Wiesel's commitment to tell the stories of people who have died so that they can live on within us, and so we do not forget them or their experiences. I'm sure that encountering this idea is what caused me to remember and write down the scenes that follow. It is fascinating to me that the vignettes which I felt compelled to write were not stories which I had written before or said out loud to anyone, including friends. I tell stories all the time, especially in HIV workshops, about the people I've known—but not these particular brief narratives. Their power was evidently such that I could not share them before, which is unlike me, who usually tells stories to

anyone who will listen.

### SO WHAT?

Before moving on to the vignettes I wrote during the few days that I was reading Brown's study of Wiesel's work, I want to raise the question of what all this has to do with professional helping. So I sometimes feel sad, so what? As I tried to decide whether it was all right to share these experiences, I asked myself that question many times. As most social workers are, I have always been careful of what the profession calls "boundaries," striving to be constantly aware of removing my own "stuff" from the work so that I can be more effective and more fully present for those who are asking for support. I have been known to say, "It's not about me," and I have fully believed that to be the case. I'm not at all suggesting that we disregard ethics, boundaries, objectivity, and being consumer-centered; I would be horrified at those suggestions. What I am prepared to say, however, is that after we have left the encounter or interview, after we have done our best to keep our biases out of the interaction, after we have put our own feelings aside so that we can do the difficult tasks we face, it is sometimes useful to acknowledge that our clients touch us, that our work is made better by our being reflective, and that we are not immune to bone-crunching grief just because we are paid professionals. I am also suggesting that it is sometimes appropriate to break our silence about the people who have touched us and taught us, and who can no longer tell their own stories. The reason to bear witness to the devastation of the HIV

epidemic is so people will be reminded that our world has paid and continues to pay a precious cost, and that the individuals who have died are missed and mourned. The question is not whether we as helpers will be saddened, will feel diminished by loss, and will sometimes feel too weighed down to continue. We most certainly will. The question is how we react and behave when that happens, how we are able to use the pain to enlighten our responses to others, how we are able to refresh ourselves in a way that brings meaning and longevity to our practice, and how we are able to present our memories so that people do not take those losses for granted. We can make our work a memorial to those who have died and a tribute to those who are struggling. We can see to it that our grief results in activism rather than burnout. We can break our silence about how the epidemic has personally affected us. That, I believe, is what telling the stories of the dead has to do with helping.

### MY STORIES<sup>2</sup>

These are not the stories of other people; these are my stories. They were personally experienced, have been reconstructed, and are entirely my viewpoint. However, they are remembered and told in honor of the people who inspired me and taught me. I present these memories as they occurred to me, without explanation or analysis. What follow are eight vignettes concerning the deaths of friends and clients; the last story concerns only me. I regret that I cannot be an elegant, effective, and impassioned storyteller like Professor Wiesel is; these ghosts which haunt me deserve a better witness.

### ESSIE<sup>3</sup>

I have no idea how a person's heart can fool her in the face of all evidence, but I do know that I was thoroughly convinced that Essie would not die. Could not die. What was I thinking? Well, I was thinking that she would never leave her children. They needed her. She was devoted to them. One

of the children was HIV-infected. But where did I get the notion that death happened only to people who had nothing to live for? My head, my experience, my common sense told me otherwise. Except that day. All I knew that day as I sat by Essie's hospital bed was that she had always put her children first and that it was not possible that she would leave them. I was fairly new to HIV work, but that's no excuse and not really an explanation for my self-delusion. I'm amazed now that I think of it. I looked right at Essie, saw her struggling to breathe, saw the distant look in her eyes, and did not invite her to say anything real to me. I did her the terrible disservice of denying the obvious. I took her hand and, rather than saying goodbye or saying nothing, I said something insipid about hoping she was on her feet soon. Even more strangely, I actually corrected one of the nurses who told me that they didn't expect Essie to make it. From my high horse I said, "People do recover from pneumonia, you know. She's a strong woman. She'll rally." The nurse let her incredulity show on her face. I wonder if she laughed at me after I left or just shook her head in disbelief.

When I arrived at the workshop I was to do in another town a few hours away, there was a message waiting for me from my supervisor, Bill, that Essie had died right after I left her. I felt so enormously stupid. Incredibly, I also felt somehow lied to; fooled. It took me a couple of days to realize that I had lied to myself, that's all.

What Essie taught me by her death was profound: that HIV disease is more powerful than anyone's wishes, that death can win no matter what you have to live for. All of the romantic and naive notions that had been put into my head about illness and survival fled with that phone message.

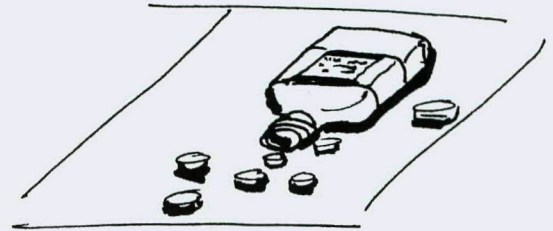
I paced and fought tears as I was preparing to speak before a group of counselors. The topic, unbelievably, was bereavement. When I got to the hotel that evening after the workshop I called Bill and spoke to him briefly, trying to explain the disconnection between what I'd seen before me and what I

had chosen to believe. I felt that he was surprised by my having convinced myself that she wasn't going to die, but I could also tell that he understood it completely. I had another presentation in the morning, so I assured him that I'd get some rest and that I'd be fine. When I awoke the next morning, the message light on the phone in the motel room was lit. When I called the desk, a woman said, "Oh, yes, a "Bill" called. Around midnight. Said not to disturb you. The message is, 'I love you.'"

### JASON

When Jason joined the support group he seemed confident, likable, easy going. He had a boyish, crooked, ready smile. What he was proudest of was his rising career as a restaurant manager. He defined himself as a hard worker and a good guy. One day he showed up at my office talkative and agitated after a sleepless night: after years of outstanding evaluations, he'd been suddenly fired from his job with no warning. He had been out sick the week before, and he feared that he had been let go because upper management suspected that he had AIDS. Through six months of our working with him on legal recourse to address the discrimination, he grew more and more hopeless and depressed. He stopped looking for another job. He talked about having no purpose. I realized that having been rejected long ago by his family, and not having a lover, his career had become his source of his self-identity and worth. He told me that without that job he was nothing. He started seeing a psychiatrist and taking antidepressants. When he showed up unexpectedly in my office a second time, he stood directly in front of my desk, looking down at me, saying nothing. I studied his face, feeling scared, and something made me say, "Jason, are you planning to kill yourself?" He silently nodded yes. My gut twisted. At my urging, using few words, he outlined his plan to take sleeping pills. He then agreed to hospitalization, again saying little. When he was discharged two weeks later, he took an overdose of sleeping pills on his second

day at home and then called an ambulance. After that second discharge from the hospital, he hung himself in his living room. He was found and cut down by another member of the support group who had gone by to pick him up for a movie. Jason's suicide taught me that discrimination and injustice can kill.



### ROBERT

When I met Robert, I was a little frightened by what I experienced as his hyperactive energy, fidgety mannerisms, and streetwise speech patterns. But very quickly all of that junk fell away, and when Robert got up to leave after an hour of chatting with me, we hugged. Rather, he earnestly, warmly, and quickly reached out to embrace me as he thanked me for my time, and I returned his hug without feeling any qualms or questions about appropriateness. He became a regular participant in the support group I facilitated, and I always looked forward to his remarkable humor and wisdom. One night he confronted me, asking this question not once but three times, shocking me and leaving me speechless: "CP, you come to group every week and listen to all of us, and I want to know how this epidemic is affecting *you*."

Once I surprised myself and Bill, my boss, in a professional workshop by using my relationship with Robert as an example of how empathy and partnership could bridge seemingly insurmountable differences between helpers and consumers. I told those social workers and nurses that this man had taught me so much and said, "I never would have predicted when I met him

that I would come to love him so much.” I saw Bill raise his eyebrows and heard his intake of breath; later he told me how moved he had been by this disclosure. The mutual regard went verbally unacknowledged between Robert and me for the next few years, until Robert told me in a telephone conversation late one Friday evening: “I’ve only trusted and loved two white people in my entire life. My doctor is one, and you’re the other.” I still count that as one of the most generous and touching things ever said to me. This is the biggest lesson he taught me, a lesson which now resides deep in my gut: barriers can be transcended.

Robert called me at home from his hospital bed on a Saturday morning: “CP, it’s not good. Can you come see me?” I promised to visit that morning. When I hung up the phone, Donnie called to say that Jason had made a suicide attempt with pills and was back in the psychiatric hospital. I hung up and sat on my bed sobbing. I then called my friend Joseph, who was also a volunteer, to accompany me to see Robert and Jason.

When I entered his room, Robert began to talk incessantly, rapidly, seeming alarmingly manic. He started by saying that he knew he was in great danger but that he wanted to fight like hell to get well and go home. His lover Patricia was there as well, sitting by his bed in a chair and not talking much. I sat on the other side of the bed and Joseph stood at the foot of the bed. Ironically, during this visit I didn’t feel connected to Robert. For the first time since we’d met I felt bewildered by him. I felt distanced by his outpouring of frantic words and helpless in the face of his panicked attempt to make sense of his life by talking about it nonstop. After an hour I arbitrarily decided to leave, not understanding what to do for Robert and feeling tearful and profoundly out of control.

In the hall Joseph hugged me while I cried a little. He asked if I was ready to go see Jason, and I reacted strongly. “No! I can’t see someone who’s trying to die after seeing someone who wants to live so much.”

I was aware of being enraged at Jason and at the same time felt that my reaction was unfair and unprofessional. I told myself that I would see both Jason and Robert later. I never saw either one of them again.

I was at my desk when Joseph called to say that Robert had died. I checked out how Joseph was reacting to the news, but I wouldn’t respond to his questions about myself. I felt numb, frozen, without response. I hung up the phone and continued working on the grant I was writing. I told myself to keep working, that lots of people depended on me to keep working. About thirty minutes later Bill slouched in my doorway to ask me a question about the grant, but stopped mid-sentence to say, “Honey, what’s wrong?” I didn’t look at him as I answered “nothing.” He stepped into the room and closed the door. “I want you to tell me.” I said “nothing” again. He patiently waited out my silence, standing still in the middle of the room. Realizing that he was not going away, I sighed and said, “Robert died.” Bill groaned and started to cry, which surprised me, because Bill hated to cry and rarely did.

As he sat down in a chair, rubbing his eyes, he simply said, “Ouch. That one hurts.” I remember looking at him in disbelief, a little angry, but at what I didn’t know. Then I started to cry. I guess I felt somehow that it was okay to fall apart now. Bill came around the desk, handed me a tissue, and held me for several minutes. When I quieted, he went back to the chair and we sat for a minute or two in silence. Then he said tentatively, “CP?” I looked up at him. “Your mascara’s running.” Then suddenly we were both giggling, covering our mouths and not wanting anyone to hear us. What a weird moment that was, but at the time it felt natural, intensely intimate. I know that our playfulness was coming out of our love for each other and not out of disrespect for Robert. I took a mirror out of my desk drawer and wiped away the mess. I handed him pages of the grant as he stood to leave. I stood up and we hugged a long time. I did not at the time notice, much less

reflect upon, the roller coaster nature of our days: grief, joy, work, friendship, anger, love, all inseparable and intertwined. We just carried on.

### **DONNIE**

I had never known Donnie to question or confront anyone. He was a quiet, wizened, unshaven and unassuming man who disclosed very little about himself. He'd told me that he'd been a traveling carnival worker all of his life, and I figured that nothing rattled him. An hour after Jason's memorial service, he was intense and intent as he sat in the chair in front of my desk, still wearing the suit he'd worn to the funeral home. With an animation and sense of purpose, which I'd never seen in him before, he got right to the point and said his piece all at once. "CP, I need to understand why you didn't go to Jason's funeral. Robert's either. I'm asking because I'm afraid that you won't go to mine." I was stunned. But I did not feel attacked or invaded; I felt trusted and honored. I considered for a minute all of the deflections and reflections that I could offer him, and then I decided to be as simple and direct as he had been. "Donnie, I don't go to funerals at all. I haven't been to one in 20 years. They don't comfort me. I probably won't go to your funeral, but that's not because I don't care about you. It's because I remember people privately, in my own way, alone." He seemed to be taking this in for a minute. He then put his hands on his knees, nodded, said, "Thank you for telling me that." Then he smiled at me and left. Donnie had no formal education, was not someone I would have labeled a great communicator, and was not especially forthcoming about his own thoughts and feelings. Yet this brief conversation was deeply meaningful to me and taught me more about congruence and self-disclosure as a helper than any other I've had before or since. It taught me to honor questions and to only offer truth in return.

About a year later I got the call that Donnie was unconscious and dying. I left the office immediately and drove to the

hospital. When I walked into his room, I saw that he was sleeping with his eyes open, which is a very bad sign. I looked at his ex-wife and his adolescent daughter; his daughter had tears in her eyes; his ex-wife shook her head slowly; none of us spoke. I went to Donnie's bed, lowered the rail, listened to his labored breathing, and began stroking his forehead. I was shocked when my touch actually roused him. Unbelievably, his eyes focused on my face. I continued to stroke his face and head while he stared at my face. It was unclear to me if he would be able to hear me, but I said it anyway. "I love you, Donnie." I'll never forget the next moment, as startling as it was moving. Once again, he got right to the point. Donnie answered clearly, "I love you too, CP," and then fell into his unfocused, eye-opened, panting unconscious state again. I stood there for a moment, feeling like I'd just received something magical; an incredible gift. I left the room after a few more minutes. He died an hour later.

### **MARK**

It happened in the usual way: someone called me to say that he was in the hospital, not expected to live through the day. Dying so often grabbed people quickly, I'd found; the last battle with HIV sometimes came completely without warning. It always seemed impossible to me to be prepared for anything. When I entered Mark's room, I saw that Frank was on the far side of the bed, facing the door, crying silently. I was surprised; I hadn't realized that they knew each other. I wasn't sure that Frank would remember who I was. He had seen me only in the context of being Bill's friend or Joseph's friend; he was friends with both of them. He looked up and said quietly, "Hey, CP, come on in." I nodded to him, pulled a chair to the opposite side of the bed, and sat down without saying anything. Mark was clearly unaware of both of us. I listened to Mark's loud, arrhythmic breathing, hearing the congestion in his lungs. I reached up to stroke his face, which was very hot. I felt so very tired of this. Strange, but I didn't

realize that I was on the verge of tears until I actually started crying. I was embarrassed to be crying in front of someone I didn't know well, someone who would probably expect me to be "professional," but Frank just smiled at me in sympathy. For several minutes I sat with my eyes closed, holding Mark's hand. The first words I spoke in that room were to Mark as I kissed his forehead when I stood up to leave and said very quietly: "Goodbye, Buddy." I jumped when Frank immediately said loudly and with energy, "DON'T tell him goodbye! How DARE you give up on him!" Now I was concerned about having offended Frank and was a little taken aback by the strength of his anger. He could have interpreted what I said in a variety of ways, I suppose. I just said, "I'm really sorry, Frank." Then I turned and left.

#### **FRANK**

I was very surprised when Frank started calling me. He had always told his friends that he wasn't interested in getting social services, that he was fine. Now he was getting sick and was willing to have long telephone conversations with me about his fears of being incapacitated. Very quickly he became confined to wheelchair and bed. He was wasting and had become incontinent. His ex-lover and mother moved in with him. But Frank issued the order that they were the only two people who would be allowed to see him from here on out. For the last six months of his life, he didn't waiver from that demand. He continued to talk with me freely on by phone, and would give me permission to come over to his house, but I would spend the time downstairs in the living room talking with his mother while he rested or slept upstairs. Each time she would go and ask him if I could come up, and each time the answer was no. This was the consistent answer for his friends as well. He was clear about his reasons: "I want everyone to remember me the way I was." Unreasonably, I felt like I was letting down Bill and Joseph somehow by not being able to check on Frank myself. His friends were

hurt and I was frustrated, but he was steadfast. There would be no goodbye scenes with visitors. I knew that his decision to isolate himself had nothing to do with me, but occasionally I would remember his enraged reaction to my telling Mark goodbye, and I would wonder.

#### **LIZ**

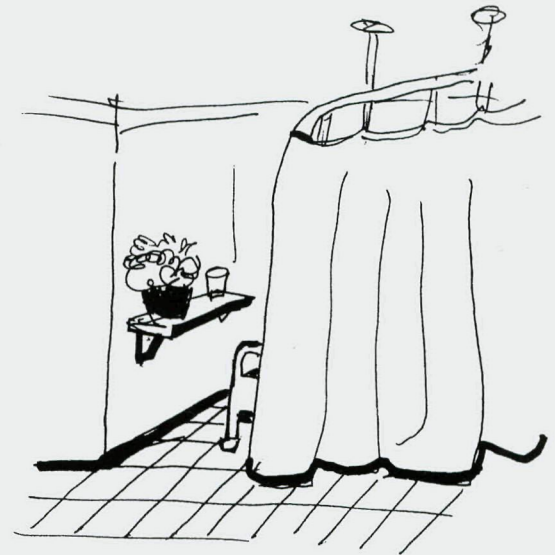
When I visited my friend Liz at home in early 1993, I was horrified. I'm using that word deliberately; it's no exaggeration. She was unchanged—still effervescent, funny, a good listener, exuding a warm happy love for her family and friends—but her petite body was unrecognizable. Her spine had become terribly twisted, and she was bent almost double at the waist; her arms and hands shook uncontrollably; she shuffled rather than walked. Her body had become so deformed that she had to sit down to make eye contact with me. I worked hard not to show the immense shock, sadness, and fear that I felt. I tried to allow her to set the tone of the visit, which meant that she asked me about myself, Bill, the agency, the advisory council (which she'd helped me form several years ago). She laughed with genuine joy as she talked about her two children and her husband, took great pleasure in showing me in her new bird book pictures of the species she'd spotted at the bird feeders that her husband had hung on her deck for her. She did not skirt around her terrifying health change—she expressed great regret at not being able to complete her residency as an internist—but incredibly, she did not seem bitter or frightened.

Through the years that I'd worked with her and done presentations with her, she'd always been clear, honest, and articulate about her reactions and feelings, privately and publicly, so I knew that she was not prone to pretending. She didn't usually greet adversity passively either, evidenced by her having to threaten a lawsuit when the medical school tried to expel her for having HIV. As much as her physical appearance threw me, I was equally baffled by her obvious serenity. I don't know how to say

this without sounding either melodramatic or trite, but Liz seemed to me to glow with peace, joy, and inner spirit. I felt like I was in the presence of some kind of transcendent being. At the same time I was so very sad. Liz saw that, I think, because suddenly she put her hands on my forearm and said, "Sweetie, I'm okay with this. I really am. I know what's happening. Don't be sad." I thought it would be a challenge to hug her because she couldn't straighten her spine, but she knew what to do: she held me tight around the waist and patted my back.

This was the only situation that I can remember when I didn't tell Bill the whole truth. I did not tell him anything about how Liz looked. I did not want him to know that HIV could do that to a person's body. I knew that he loved Liz, and I knew that he was planning to go see her, and I couldn't stand the thought of his having to confront her destroyed neurological system and perhaps realize that he could face the same future. It's not that I really thought that he or anyone else could get like this; it's just that I didn't want him to witness firsthand what this virus had the potential to do to him or anyone else. The only thing I said to him about my visit with Liz was, "Don't go see her." I said it emphatically and without explanation. He knew I meant it, and he looked frightened. And he didn't go see her. I felt good that I'd spared him that visceral fear, that terrifying sight. I'm ashamed in retrospect that I did this; why wasn't I thinking of the pleasure and comfort that Liz would get from seeing him? Why wasn't I thinking that perhaps they needed to say goodbye? Why wasn't I thinking that Bill could feel blessed in her soothing presence, inspired by her courage? I was just single minded in my desire to protect him. He went to her funeral; I didn't.

A few months after her death I witnessed another HIV-induced neurological horror—this time far worse than Liz's—and this time the twisted, ravaged body was Bill's.



### BILL

This incident happened on one of the nights in mid October 1993 when I was alone with Bill in the hospital room. It was his first hospitalization; he was rapidly deteriorating from symptoms that no one understood. The doctors were still trying to find a combination of narcotics which would lessen his pain, and nothing was yet working. Bill was trying to tolerate bravely wave after wave of terrifying, horrifying, gripping muscle spasms, accompanied by the feeling that his nerve endings were on fire. Anyone observing these spasms could see the ripples in his muscles, the contractions and twists were visible just under his skin, and sometimes I would see the attack coming before Bill would allow a cry or scream to escape his lips. We tried to joke once about this being like being in labor, but the joke fell flat; this had no end, nothing good could or would come of it; no one had seen this before and no one knew how to make him comfortable. Whenever I would see an attack starting, I would scramble up into the bed with him and start frantically massaging his legs, arms, shoulders, anything to try to ease the clutching of his body. So many parts of his body would be turning against him at one time that my hands would race over him as he requested that I massage first one place then another: here, no here, no there. I would feel utterly helpless, to the



roots of my spirit. I would whisper things like “deep breaths, Honey,” “open your hands, Sweetie,” “go ahead and scream.” Hours and hours and hours of this. He was weak, exhausted, tearful, trying not to dread whatever was coming. Was I feeling demolished out of empathy for Bill, or because of my own labor and emotional strain, or both? When the spasms would stop, sometimes he would say things like, “Go on home, Honey. You have to work tomorrow.” Most of the time I wouldn’t answer that with words. A couple of times I said something like, “I can’t leave until I know you can sleep.” Once I made the joke: “Oh, don’t worry about it; I have a really understanding boss.” From the pit of his utter exhaustion, he chuckled and then choked at that.

Somewhere between midnight and one—the space between spasms had been just long enough to lull us into the hope that they were over—I saw his feet begin to curl back, his knees suddenly bend, his back arch, his arms go suddenly rigid by his sides. I quickly put my right arm under his neck, and my left hand flat on his chest, and got close to him, holding him up a little. All of a sudden it felt to me that I just couldn’t stand it anymore; that the waves of pain were climbing my soul, and this time as the gripping ripples hit him I threw my head back and cried out as pent up tears escaped. And here’s what was in my mind, as clearly as if I were speaking it aloud: “Stop it! Take me instead.” I was asking whatever capricious force was in control of the universe to substitute me for Bill. Me, a solid, unshakable atheist for over two decades, prayed. I prayed: “Let me feel this pain instead of Bill.” This was my only thought, a pinpointed focus, and for a split second I wasn’t sure that I hadn’t said these words out loud with my sobs. “Please. Take me. Leave him alone. Leave. Him. Alone.”

Then it was over. That particular wave of spasms, his cries, my sobs, and my prayer. It felt like there was profound, intense silence in the room. There were no sounds coming from the halls either. Still-

ness. But stillness which contained no peace. Stillness which was the aftermath of terror. I heard nothing but Bill’s panting. Without speaking I wiped the tears from his cheeks [since he couldn’t move his limbs himself], settled him back on his pillows, repositioned his arms and legs, and absent-mindedly held his left hand, which no longer had any feeling in it.

I didn’t realize it right then, but my life had just been changed. Forever. How like a cliché that sounds. But sometimes we do experience defining moments, split seconds when something shifts so radically that the previous normal state is no longer attainable. Now, as I write this, almost six years after this incident, I am tearful again and feeling again the truth of it. I was never to be or feel the same. For a few seconds there, with all my heart and mind and will, I had fervently wanted to die so that my best friend would not be violently abused any longer. This feeling was far different from a suicidal impulse; this overwhelming desire was not battle fatigue or being in any way ungrateful about living. Bill had taught me over the past few years to be profoundly grateful for the gift of life. I have no enlightening words for this event; it’s a tale that can’t be told.

This incident was a snapshot in an ongoing movie: my witnessing and feeling the unspeakable demise of a soul mate, a friend who was dearer to me than anyone else before or since, who had been a mentor I almost worshiped in my admiration. And this is the fact that six weeks later literally changed my life: I survived and he didn’t. I entered territory where I had no passport: the holy ground of suffering, undiagnosed sickness, freezing fear, uncontrollable pain, unspeakable humiliation. And then I came out of this forest and Bill didn’t.

Each day since then I have been consciously aware, at least once during the day, that being alive is a random, capricious situation that I didn’t earn and that would be withdrawn at any time. It’s an undeserved gift. All I can do with this awareness is to try and behave so that Bill would be proud

of me. To struggle to find ways to give witness to the lives lost, and to make my work a memorial to Bill and all the others I knew, cared about, and watched die. Yet these are goals which can't actually be fully accomplished. I am unworthy of being their translator; I don't have the skills or the fortitude to be their vessel. I ask myself frequently: for what reason was my life spared? The only thing that is ever clear to me is that I have a life and they no longer do; what that really means, I have no clues.

### ME

This incident happened in the summer of 1994. Bill had died the previous Thanksgiving, I was trying to do his job and mine, and I had already made plans to leave the agency and the state. I wanted nothing more than to escape from the emotional pain I was living with daily.

I was in a meeting. I had been appointed to a statewide HIV-prevention planning group of 25 members and had quickly become utterly disgusted with the slow committee process, enraged that the infighting was—in my opinion—costing lives as we argued. An outside facilitator had been called in to take us through a weekend retreat so that we could get along well enough to write a statewide HIV-prevention plan. When this incident happened we were in the introductory process; approximately 30 people were sitting at tables in a rectangle, saying their names and what brought them to this work. For some reason that Saturday morning I was feeling grief as if it were physical weight. It felt like sitting in a world with suddenly extra gravity; I felt that I was being pulled down in the metal folding chair. Throughout the introductions (which seemed obscenely cheerful to me) I was looking down, unmoving. I am not aware of feeling the burden of the epidemic as profoundly, before or since, as I was that day. My mind was saturated with memories of the scores of people whom I had cared about over the last eight years who were now dead. I remember realizing that morning that it felt like my insides had shriveled

up a while ago and I hadn't acknowledged it until just then. I felt physically flattened. My sadness was profound; it was both specific and general; it felt unbearable. I couldn't listen to any of the introductions; I was unwillingly reviewing the march of humans—children, teenagers, men, women; faces of all conceivable hues; wasting, feverish bodies; pleading, sad, scared eyes. And over all of them was Bill, my heart. I was feeling utterly devastated and hopeless.

A couple of times I became vaguely aware of the consultant, Moss, sitting beside me to my left, and finally I realized with surprise that he was sitting as motionless as I was. He wasn't even looking at the people who were introducing themselves. I guess that because I was sitting beside him and we were introducing ourselves in order in a circle, I ended up being the last to speak. I remember the effort it took for me to rouse myself and pull myself forward and engage my voice when I realized that everyone was looking at me. I felt uncomfortable with the attention, but at the same time I didn't really care. My friend Michael (he's now dead from AIDS too) was sitting to my right, and he put his hand on my right arm as I leaned forward with my elbows propped on the table. What I said, quietly and slowly, was very close to exactly this: "I've been in the HIV field for eight years. During that time I've experienced the deaths of about 300 people I cared about...clients, volunteers, board members, friends. Recently the man who was my best friend, my teacher, my boss, died. His death made me realize that I can't do this anymore. I'm moving to Chicago to go school." Even though the group members had to be surprised by that last announcement, I noticed no movement in the room. I felt at the time as if I had accidentally frozen everyone. There was a fairly long silence after I stopped talking, but I don't think that anyone thought that I was going to say anything else. They were all waiting on Moss. Then he cleared his voice, sat up, looked at his folded hands, and turned his head to me. What he said was very close to exactly this: "When you were

speaking, I was having a flashback. Post-trauma stuff. I was back in Vietnam. I was smelling burning human bodies. A pile of corpses, burning.” He paused for a few moments, looked out into the room, and continued by saying that he’d been very aware of my stillness and my grief throughout the introductions, and it wasn’t until I spoke that he’d understood the reason for my sad energy. He told the group that he’d just now made a visceral connection between his war experiences and how others experienced AIDS. And right then I had absolutely no vision of how I was going to leave that room and go on.

#### CODA

What happened next? I did indeed go to Chicago for a doctorate and am now teaching social work at Boston University and doing as much HIV advocacy and education as I can. I am still struggling, as do all HIV practitioners, with how to do a modicum of self-care while the epidemic rages on. But I learned firsthand that burn-out is temporary and survivable, a vital lesson for social workers and one that we don’t communicate often enough.

Originally this article ended with my sitting unnaturally still in that committee room, realizing the depth of my trauma response and my despair at not finding the strength to go on. I didn’t think I had anything else to say about grief, memory, and honoring the dead. But when the article was accepted, the reviewers and editor wanted me to add an end piece reflecting on where I am now and what I think and feel about these memories. Surviving burnout is one piece of this coda; the role of memory is another.

After I wrote this article in August 1999, Professor Wiesel graciously allowed me to audit his course on the literature of memory and reconciliation. During the fall semester, week after week I sat in this class, in awe of the horrors which human beings are able to survive and deeply moved by reading testimonies in which authors strive to give testimony to keep the memory of the dead

alive. It was an extremely disturbing yet uplifting experience. I was constantly shocked and amazed at how cruel life is and how resilient the human spirit can be. Through this process my commitment to attempting to lift up the stories of this epidemic intensified as well. Upon learning that this small memoir would appear in print, I felt a confusing mixture of anxiety and relief: anxiety that I had not done justice to the memory of these individuals, and relief that someone else might read of their worthy lives and how deeply they had affected me. Storytelling is therapeutic, even while it leaves us feeling exposed.

I strive each day to make my work a memorial to the people I’ve known who died from AIDS. It’s a burden, but it’s also an honor. Sometimes friends and colleagues ask me what keeps me going, but I don’t always tell them this raw truth: that I carry within me the memory of scores of souls who inspired and taught me as they faced death, and I feel that if I don’t continue to try to use what I learned from them, they will die again. □

#### Author’s note:

The author wishes to acknowledge Professor Elie Wiesel, and to thank him for reading and commenting on this article.

<sup>1</sup>Brown, Robert McAfee (1983). Elie Wiesel: Messenger to All Humanity. Notre Dame, Indiana: Notre Dame Press.

<sup>2</sup>I met all of the people in these vignettes while I was a case manager and program director at the Palmetto AIDS Life Support Services in Columbia, S.C., from 1988 to 1994.

<sup>3</sup>All names are pseudonyms except for Bill.

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