

Chapter 3 – All the Lonely People

Death by the numbers can be staggering.

I would be working with roughly 15 to 25 hospice patients at any given time. About half of my caseload would die each month, invariably making room for more. That amounts to 10 to 15 deaths a month, maybe 125 a year. I did not go to all of the funerals, perhaps a third of them. In three years, I met about 300 people who would die well within the span of the same time period.

The official line at the hospice was that we did not “help people prepare for death,” that we instead “helped them live life until the end of it.” So untrue. It would have been cruel to not prepare someone for what was coming, as best we could.

After about eight months on the job, things became easier for me. I am not sure why. I suppose I got into the rhythm of working in the hospice environment and became somewhat hardened. I had been through a lot of death and dying by then, and so perhaps I had more confidence in my effectiveness. There is also this weird gallows humor that happens in hospices as a sort of coping mechanism—we would joke about a family that needed “slap therapy,” for example.

Whatever the case, I stopped crying all the time.

By then, I had also built up a couple of relationships with other staff members and had some degree of comfort there, but we still did not talk much about our cases. We just sort of ignored it, though we did talk about the agency and how dysfunctional it was. That was good for a laugh.

None of this is to imply that the work ever really got easier. Sometimes it would be a case of hurry up and wait, and I got pretty good at that. If I was on call during the weekend, it was almost certain that I would get at least one call, so I might as well wait for it.

One morning at around 2 a.m., the phone rang—a rude awakening, even when you know it may be coming. The sister of one of my patients, Ronnie, was very, very upset. Ronnie was going to die soon. The sister had thought she still had a couple of months to go, but things had taken a sudden downturn. She had finally grasped the true reality of her sister’s impending death.

The woman on the phone was on the verge of hysterics. I remember asking her some specific questions, partly as a way to calm her down in the dark as I pulled on some semi-professional clothes, trying not to disturb Ed or the sleeping pets. Putting the dogs out at 2:15 was the last thing I needed at this point. Time was of the essence.

The agency’s rule was I could not talk on the phone while I was driving. The problem was Ronnie’s death was very likely imminent and she was a good 20 to 25 minutes away. At the same time, the sister seemed to need immediate support. It was sort of a balancing act.

The sister did not know what to do and was scared to be alone. It is very hard to be the only one there when a loved one is dying. You do not want to leave them, even for a second. She sounded a little better by the time we hung up in the car. I quickly turned the key.

As I was frantically driving a late-night commute to a nearby town, I prayed Ronnie would survive the drive. It was so tempting to speed, but safely obeying speed limits was an agency rule. There is not much traffic at that hour, luckily.

When I finally rang the doorbell, a 30-something woman with messy, short blond hair, a red nose and sad, droopy eyes met me at the door. She nearly collapsed into my arms, but just as quickly stepped back, wiped her face with the back of her hand and mumbled, “Sorry.”

She grabbed my arm and pulled me into the living room, where a hospital bed was set up.

Thankfully, Ronnie was still alive, sleeping quietly, breathing slowly and unevenly.

I tried to calm down her sister and walk her through what was going on, explaining what the symptoms meant and what she could do in these final moments. I suggested that she sit and hold Ronnie’s hand, talk to her and try to keep her sister calm. I told her that even if a person is unresponsive, we still believe that they can hear us.

It was not long before Ronnie died quietly and peacefully as her sister lovingly held her hand.

This was the kind of scene I would become accustomed to. A lot of people die at night. Perhaps it is easier to relax and at a time when we are used to falling asleep.

Some people even seemed to decide when to die. They simply let go. Many would die all by themselves. A family would hold vigil for a long period of time and then step out of the room for five minutes to have a conversation or go to the bathroom. When they got back, their loved one was gone.

There were people who did not express a lot of emotion to their families during those moments. Sometimes they would not even say, "I love you."

One question came up a lot in my conversations with patients: "Who are you having a hard time saying goodbye to?" Sometimes the patients would want me to talk to their friends or family members or would at least want me to be there when they talked to them.

Other patients were mainly concerned with how their family was handling the situation. One was Monica, a 27-year-old nursing student with an inoperable brain tumor. She had short blond hair, large round blue eyes and a slight build. She had fallen down and had a seizure outside her classroom at Stanford Medical School one day. There had been no history of medical problems.

Monica was basically my daughter's age. Most of the young people I saw died of brain cancer. I did not do much life review with Monica or the other younger patients. Sadly, there was not a lot of life to review. Those cases took more of a toll on me than the older folks who had lived full lives. Fortunately, I never had children as patients, though I had colleagues who did.

Monica's family had brought her to a hospice wing in one of the local nursing homes. She had been given three months to live.

"Well, I guess this is it," she said when I first visited her.

In general, people were either pretty calm and settled about death or they were pretty anxious and unfinished about it. This young woman was relatively accepting of her situation, lying on her bed, surrounded in this facility by people old enough to be her great grandparents.

"This isn't what I wanted," she said with a sigh. "This isn't how I thought it would be, but here I am and I want to help my family get through this."

Seeing her family in such emotional pain was very difficult for this young woman. She wanted me to help them more than help her. She was really brave. All you could do is just be with the family. There is not a lot you can say—and sometimes that is what you say.

This particular family was resistant to help, however. They wanted to be there for each other, but did not really want assistance from an outsider, which I can certainly understand. The mother's tear-stained face told the story of practically no sleep and countless hours at the computer and on the telephone to hospitals and specialists across the country looking for a miracle cure.

We did have one meeting with the whole family and the doctor, who went over what to expect in the final days and hours so they could "prepare," as much as they could. It was really tough.

I went to Monica's funeral and burial. Her mother collapsed as her daughter's body was lowered.

I ran into her a few years later and gently asked how she was doing.

"Well, I don't cry every day anymore," she said.

Unfortunately, not all families were as emotionally available as Monica's. I remember a woman with pancreatic cancer whose husband played golf every day. That just blew my mind. I don't know if he was in denial or if that was just his way of coping with it all. He seemed kind of nervous. Maybe he was uncomfortable being around her because he had no idea what to do.

There was another case where a woman had been very, very close to her 12-year-old grandson, but he refused to see her as soon as he found out she was dying. He just could not handle it. That really hurt his grandmother, until she began to understand.

Another woman had a huge melanoma on her back. It was enormous and black. I could not help but think that if her husband had ever helped her undress, he would have caught the cancer sooner. It makes me cry for all those women out there whose husbands do not want to look at them anymore, or whose wives are too embarrassed by their huge bellies to allow their husbands of 25, 30 or 40 years to catch a glimpse of a strange-looking mole.

While apparent indifference was something I sometimes had to face, other families were downright hostile to the whole idea of hospice care.

Kim, a children's author, was very distraught about not being able to finish her last book. I could not help her with that, but she and I became quite close in a certain way, at least I thought so. When Kim was dying, her son would not let me say goodbye. He was very "anti-hospice," for lack of a better word. He basically fired me from the case, and it hurt a lot to be dismissed like a servant.

Some family members did not seem to realize that a hospice social worker could provide them with practical information and resources that might be helpful, such as books to read, perhaps a support group, or just ironing out the details of the funeral. I was certainly willing to meet families on their own terms. But a few seemed to think I was just there to dig around in their psyche.

For some people, death just made no sense—at least not to them. Frank was 42 and had an inoperable brain tumor. He was a biker who went with his girlfriend every year to the big motorcycle rally in Sturgis, South Dakota. They were sweet people. Frank could not believe he was going to die from this thing, which seemed like a big nothing to him. He had no real discomfort, except for the occasional headache. He really missed riding his bike.

For obvious reasons, older people, as well as their husbands, wives and children, were much more accepting of death, and that was easier for me too. I always admired Betty, who was a resident at one of the nursing homes. She must have been 85 or so and was suffering from congestive heart failure.

Every day, Betty would look at the birds flying outside her window.

"Well, I wonder if that bird's gonna to hit the window today," she would often remark. "Because you know, when that happens, it means somebody's gonna die today. And I wonder if it'll be me."

One of the saddest cases for me was a man, probably in his sixties, who was truly alone in life—and in death. Greg had melanoma that had spread throughout his body. Nobody ever came to visit him in the nursing home, and he had no friends there either. He was certainly a loner, but he did not want to be. He was not very easy to get along with, and evidently he never had been.

Still, Greg always looked forward to my visits because I would really talk to him. It was one of those situations where a hospice social worker can truly provide a crucial service. Unfortunately, I was not there when Greg passed away all by himself. In my experience, people die the way they lived, and that was certainly true in his case. That must be the saddest—to die lonely.

All Greg really had when he left the world was regret. He had a son who would never come to see him and a daughter he had no contact with at all. He told me that he had been a bad father. I did not meet the son, who lived locally, until after his father died. He came in for about 10 minutes to perform some sort of a Native American ritual around Greg's body. Then, he simply said, "I'm done," and then left the room with little emotion. It was quite unusual.

I vividly recall another patient story with a near-opposite situation of amazing tenderness. It was a long-married couple who were extremely close right until the very end. I cannot remember Matt's exact diagnosis, but he had central pain and a constant burning sensation throughout his entire body.

I met Matt the day before he died. His wife was Janet. It was snowing that day—big, soft and beautiful. It must have been early spring. I walked up the four steps and rang the bell. The door opened and a petite woman about my age with short brown hair and large brown eyes kindly swung the door open and said, "You must be Kathy." The living room was very warm—not the temperature, just inviting and comfortable. I felt right at home.

"Where would you like me to put my coat? It's a little wet."

She took it for me. She offered me coffee and wanted to just sit for a few minutes before I met her husband, and I thought that was a good idea. We spoke about the illness first, how long he had been diagnosed. Their kids—two daughters, 27 and 29—both lived in town, one right there in the house, but they were not really there for Mom or Dad emotionally. That was very difficult for Janet.

"What's hardest about it now?" I asked.

After a long pause, she said, "I'll show you when we go upstairs, but I can't touch him anymore. It hurts too much. He just can't tolerate it. I can't even hold his hand or finger or put my foot against his toe. It's so bizarre and crazy and wrong. We've always had a very physical relationship, not just sexually, although that was great too, but just physical snuggling, huddling, holding hands. Now, nothing. It's like he's gone, except he's still here and they don't know for how long."

Janet did not know how much more she could take.

"It's torture. I adore him. I love him," she said.

Janet wanted to be "real" about her situation, but did not have anyone to talk to, except me. I suggested she get a journal and start writing her feelings, hiding the journal from her daughters, and even destroying it after she had written it, if she wanted to. I suggested she write it out as if she were talking to me. She liked that idea.

We went upstairs. It was a dark room with two twin beds, barely touching. Matt had very sad eyes, drugged eyes, heavy breathing, somewhat labored. I asked if he needed anything.

"No," he said. "Talk to my wife. She needs you, I think."

"Are you uncomfortable?"

"Yes," he said slowly.

I suggested the nurse could help with the pain, at least the physical pain.

"I want to say goodbye to my girls if they'll let me," he said.

He closed his eyes for some rest.

The next day, Matt passed away.

Just as they were about to remove the body, Janet fell into my arms.

"I didn't think it would be this hard," she said.

A short time later, we sat with her daughters and they discussed the funeral arrangements, Janet was still clinging to my left hand. The young women were mostly quiet, occasionally wiping away a tear. Janet stood up. I followed her to the door.

"I hate to let you go," she said, "but I know you have other work to do."

As I left, walking down the front stairs, I felt a deep respect for Janet, for how she handled losing her love. I also felt good about the job I had done, basically by just showing up and being present. I guess that is what it is all about. She was very disappointed when I was not to be the promised grief counselor, but that was our policy. Bereavement stepped in and we disappeared.

As hard as that was, the most difficult death for me was Tanya, a 24-year-old dancer with leukemia. She was delusional and highly anxious at the end. When I got there, she was lying in bed, moving around pretty uncomfortably. Unfortunately, Tanya died before the nurse could get her calmed down. It was not a peaceful death. I only had one day with her. Tanya's parents were so traumatized to watch their young daughter suffer that way. Her mom collapsed with grief.

As I helped the funeral director move Tanya's body, I remember being shocked at how feather light she was. My voice caught in my throat and my eyes filled with tears as we lifted her off the bed. Tanya was so young. I could not help but think about my own daughters.

In a much different way, there was another case that was just as tough. In fact, it nearly ended my hospice career. From a purely professional standpoint, it was probably the worst.

It involved George, a dying father who for whatever reason did not want to see his daughter, Amy, who had flown in from Ohio for an 11th-hour visit. My heart tugged for them both. Reconciling before death is beautiful when it can happen, but I also realized that it was not always possible.

I had no idea what the heck I was going to say to Amy—and before I could get my thoughts together, she walked in the front door.

"Where's my dad?" she asked frantically.

I calmly introduced myself and said I needed to speak with her for a minute. She understandably looked frustrated at this unknown person who wanted to talk to her.

"I'm sorry," I said, searching for my words. "I know you came all this way to see him, but George doesn't want to see you."

It was like a bomb dropped.

Amy took a moment to digest what I was saying.

"Of course, he'll see me. I'm his daughter," she said, clearly indignant and emotionally hurt.

"What right do you have to keep me from him?"

"It's his request, not mine. It's his wishes we have to honor."

"But why?" Amy said, now more sad than angry.

I struggled to answer a fair and sensible question.

“I don't know, but he must have a reason.”

That was the best I could muster, but it was not the right thing to say at all.

Amy flew off the handle.

“What right do you have to say that it's my fault?” she shouted. “He loves me. I know he does. You need to step aside.”

I explained that I was not going to do that, and that she needed to leave the house.

Finally, she left, but warned she would be back.

I left the house too and sat in my car for a while. I realized now that I should have called my supervisor, but I was so used to handling things on my own. Frankly, the idea of asking for help did not even occur to me.

Unfortunately, that is not the end of the story. Several weeks later, I was told that Frank, the hospice's executive director, wanted to meet with me. Amy had written an angry letter of complaint. I went pale. I immediately felt scared and embarrassed. I was not permitted to see the letter before the meeting, which seemed unfair.

My supervisor, the RN, another team leader and the executive director were all seated in this small room. As I walked in, I felt vulnerable. Frank explained that he had received two phone calls, and now this letter from Amy, saying that I had—of my own volition—prevented her from seeing her dying father, that I was a horrible social worker and that such an uncaring person should not be allowed on a hospice's staff. I should be fired immediately for incompetence, she demanded.

I felt completely humiliated. Was I really incompetent and a bad social worker?

I tried to explain, but Frank interrupted, accusing me of mishandling the situation.

My supervisor tried to come to my defense.

“Let's give Kathy a chance to explain.”

I described the events, the daughter's insistence and the dad's need to have his wishes respected. I did not handle this the best way, I said, admitting that I am not the best at conflict. But I felt like my job was to protect the patient's rights, not the daughter's. I could have suggested Amy write him a note, but I did not think of that at the time.

I was asked to leave the meeting. I felt like crawling out.

To have my work questioned and criticized that way was painful. It felt like a personal attack. I met with my supervisor later that day. It was decided that Frank would try to smooth the waters. He would acknowledge Amy's right to be upset about not seeing her father and that while I was following her father's wishes, I could have been more diplomatic.

I saw Frank later in the hallway.

“I'll be watching you,” he said, ominously.

Was this a threat? I wasn't sure what to do with it. I felt alone and scared.