A Sister's Story · *Virginia DeLuca*

I HAD A BROTHER. He died of AIDS. Mike was forty-three years old. There are pictures of him in our family album as a little boy, perhaps eight years old, all dressed up in a grey suit. All ears. Grinning. I inspect these pictures of before I was born, straining to catch any clue, any shadow, revealing that he wouldn't get to finish.

I knew him well. We were so close, that often in the midst of being overwhelmed by quick successions of intense and varied feelings, I think I should call him. Together, we would discuss in great and intimate detail the effect of his death on our lives, our families, our children, our father. This is the emotional territory we used to cover together and he's left me to do it without him.

I can picture us on the phone for hours dissecting the various facets—the expectations, the reactions, worrying about our father, our brother, comparing spouses, describing children, all the while revealing more and more about ourselves—peeling away layer after layer, and liking what we saw in each other and ourselves.

It was a great gift we gave each other. We held ourselves up to scrutiny, putting the mirror in the merciless sunshine, and we liked what we saw reflected back. How many people can you say do that for each other? How many people in your life can do that for you? Not many. Not so many that you can afford to lose one, without a great shattering pain.

Yes, my brother is really the only one I can imagine fully sharing his death with, talking and crying until we healed. He left me to do it alone.

Our separation started before his actual death. We had different places in the script. I was listening to a man grow weak and sick and trying to be brave and stoical. I listened to Mike worry about leaving behind unfinished business, unfinished work, unfinished lives of his children, his wife. I watched a man age from 43 to 97 in twelve months, his eyes growing wide and large and bewildered. I listened to a man describe despair and loneliness—as I held his hand, as his wife rubbed his head, as his children played upstairs.

I raged with helplessness.

"I watch Nancy and the kids, going about their day, carpools and home-

work and phone calls, and I think sometimes that I am getting a chance to see how they will function without me," he said. "It'll be okay. They'll be all right," and he smiled.

I ached at the distance between us. He had no idea what it would take to survive without him. I wasn't about to be the one to tell him.

"You don't understand," he said to me. "You have no idea what it feels like to be like this." He was hurt, betrayed.

I nodded and groaned at the distance again.

He was dying. I was surviving. We could hold hands. But there were precious few words to throw across that chasm and build a bridge with. I was barely able to imagine living in a world he didn't exist in. He was barely able to imagine not existing.

But even in these moments there was some laughter. In the last days before he died, in the hospital room, he woke up one morning, woke me up, for I was sleeping in the room. He woke up, giving a speech in the grey dawn light. My brother was a speech maker. He gave superb speeches. I listened for a while. He answered questions that only he heard. He invited some friends to sit that only he saw, and proceeded to tell them about his children. He talked with such joy and pride of how Greg could figure out how anything electrical worked, of Jennifer's energy, and Chris's determination. I sat in my corner, absolutely still, so as not to disturb this soliloquy.

And then he was back, needing water. I got it for him and he oriented himself in space and time. He asked if Pepper, our childhood dog, was in the hallway. And we began to talk about the hallucinations—and I felt relief. Here at least was something I could share with him, having lived through the sixties younger than he. The doctors were able to adjust whatever drug was causing hallucinations, and they eased. When the pictures on the walls started coming to life, he would describe them and laugh and ask for a drug adjustment.

Who do I make sense of this with?

He asked me in those last days to take care of his wife, his kids, our father, even oldest brother Frank. Who, I wanted to demand, did you ask to take care of me? Some things are best not spoken. He asked me to watch out for family relationships—he was worried. We are a loving family. We are not perfect. We did not always love perfectly. Not even when he needed us to.

I want to do that part over. You'd think when someone is dying that the

family could pull together and be perfect at least for a while, wouldn't you? If he wasn't dead, he and I would laugh at that fantasy together.

I knew him well—and yet I do not know how he got AIDS. If we had a few more years, I would have known. It doesn't really matter; it wouldn't change anything—except this is a question and part of a dialogue that we would have continued—if he hadn't stopped breathing, if he hadn't died.

In May 1986, I sat in a room studying the uneven grain of the woodwork. In 1986, of 250 million people in the United States, 20,000 have AIDS. Why my brother? And why, if it was going to be AIDS, did I have to be married and have three children with a man who was pathologically afraid of germs?

Earlier that spring, when he was very ill—and no one suspected AIDS or even considered it, my brother, sick and afraid, talked about dying. Not one of us could take that seriously. We were worried and concerned and hated his pain, but death? That wasn't even in the picture. But he talked on. He was not comforted by the protests of all the doctors and the nurses and his wife and his friends, who fully believed themselves when they told him to stop worrying. They were not dealing with fatal illness here. No way. He was not comforted.

"Mike," I said finally, "if you are really sick enough to die, I promise we'll give you a good death. We'll be here, and surround you in love, and take care and give you a good death. But in the meantime, please relax."

It didn't quite work out that way.

April 1986

It's been a long day. Mike is very sick in the hospital. Nancy is staying with him. Dave and I are here in their house, with our kids, taking care of their kids. I spent the day at the hospital and have now come home. I am scared, exhausted, drained. As we climb into bed, marveling how pretty this room is, how nice, how wonderful it feels, I say, "Mike is worried he has AIDS."

I too am worried, though it can't be true and there is absolutely no reason to even think it.

"If Mike turns out to have AIDS, I'm getting tested. The whole family is getting tested," says Dave.

"What? Why?" I ask.

"Because, if one of us turns out positive for the virus, and the others don't—we can protect ourselves."

Fear striking. "What do you mean?"

"If I turn out positive, I'll move out."

"That's ridiculous."

"If it turns out to be you, I'd want you to move out."

Fury replaces fear. They alternate back and forth in my body, making it hard to think. Fury/Fear. Fury/Fear. "And if it's one of the kids? You're going to ask them to move out too?"—I say snidely, sarcastically—to force him to see how ludicrous his idea is.

"Yes."

I am about to go hysterical. I can feel it rising, like vomit. "Go, to sleep. We're both tired. This is stupid. No one has AIDS."

As he snores, I creep out of bed and go downstairs in the dark. The living room is all windows and the moon is bright. I light a cigarette, drink a glass of scotch—and pray to God for the first time since I was a tiny girl.

Later that month, the doctors discover that the cause of the infection is a virulent Herpes. It responds well to drugs. Mike is feeling much better, the pain is going—soon he will be able to return home. We are out of the woods. The relief is powerful. I am exhausted.

Two days later Mike calls. "I tested positive to the HLTVIII antibodies."

"What does that mean?" I know what that means.

"It means I've been exposed to the AIDS virus and my body has produced antibodies. Only 20% of people who test positive go on to develop AIDS."

"Yes. Yes," I say. Of course. He's right. There is no need to jump to conclusions. Everything will be okay. There is no need to mention this to Dave, it doesn't even mean anything. Everything will be okay.

I read everything on AIDS I can find. I hide it. AIDS has hit the media in a big way so I am not lacking in material to read. But it is all so varied. Some pieces sound hysterical, some sound matter of fact. I have to read between the lines. What does it mean? And—what will happen? These articles talk of how it may be spread, what symptoms to worry about. They don't say

what happens when your brother tests positive for the virus antibodies and your husband announces his fear. I do not talk about this with Dave. I will buy some time.

MAY 2, 1986

Mike is home from the hospital. I call every day. He is tired. His infection is better, but he is very tired and has this terrible hacking cough. Frank, our older brother, calls: Mike doesn't sound so good. No he doesn't. Terrible cough.

MAY 5, 1986

A phone call. "I am in the hospital. I have pneumonia. The news is bad," says Mike. "I have AIDS."

White fuzz enters my brain. I will be calm. He needs me to be calm. He needs me. "Yes," I say. My knuckles hurt from gripping the phone.

"Eighteen months life expectancy."

"Yes," I say again.

"Death 100%."

"Yes," I say again.

No, NO is what I want to say. But yes I say, because I want him to know I can take it.

"Don't tell anyone," he says next. I don't expect this.

"Why not?"

"We have to protect the kids. They can't know. That town can't know. We're not telling anyone."

"What about Dad? You must tell Frank."

"Well, yes Dad, yes Frank, yes Dave. But there it stops. Promise me, you won't tell anyone else. Promise."

"You will not go through this alone," I say, fully believing the words as I say them.

My father calls and I tell him.

I call Frank.

"Mike has AIDS," I tell Dave. I say it flatly. I say it in shock. I say it in fear.

"Oh, no," he says. "I can't believe this," he says. "We can't go on vacation with them," he says.

Vacation? He has jumped around. He is in a panic. I feel nothing but fear. I am shaking. I am not even able to tell myself what I fear. I am just terrified. I look at him blankly.

I have a fantasy. I imagine all of us, friends and family gathering, offering love and support, talking, sharing, loving, crying, speaking softly, laughing. A good death. Already there are problems with this fantasy. Already it is gone: Don't tell anyone. We can't go on vacation together.

In the days that follow, the fantasy crumbles faster. Nancy calls—"Don't tell anyone. We are keeping it off the death certificate. We are keeping it a secret. The kids must never find out."

"I already told my father and Dave and Frank," I tell her.

"But I have not told anyone—not even my mother. How dare you. How dare you. Now . . ."

"I'm sorry . . ."

MAY 8, 1986

I am sorry. I am numb. Dave has said okay to the vacation—he has calmed down—if we can take precautions. Oh, I say, relieved. That is easy.

We are not telling anyone, they say. No one. How can I ask them to take precautions, if they are not planning on telling anyone? How can I tell them that Dave is afraid, when they are so afraid that people will be afraid?

MAY 10, 1986

I fly down to spend the day with Mike in the hospital. My closest friend offers to fly with me. I accept. I will be brave. I give myself a lecture: I will not be overly cheerful, or overly gloomy. I will match my mood to whatever Mike's is. I will not run from the pain of talking about death if that's what he wants. Nor will I force the talk, if that's what he wants. I will be here to take care of him; he is not here to take care of me.

I go to the hospital alone. I will get to know this place well. On the door are taped various precautions. VISITORS PLEASE REPORT TO NURSES STATION BEFORE ENTERING. I knock and enter. The nurse sees me and tells me to put on a mask. I see Mike's face over her shoulder. We shrug. I get the mask. I wait in the corner, while the nurse records temperature, adjusts the tubes hanging from the IV pole; this is all becoming very familiar. The room is full of flowers and stuffed animals.

Nancy brings him a stuffed animal for each hospital visit—"to guard you against anything bad," she jokes. The nurse leaves and now we say hello, hugging. He is so thin, I am afraid of hurting him. I see he is freshly showered and shaved. "You look great, for someone who's supposed to be sick," I say. He is feeling better. He is impatient to be out of the hospital. He wants to go to our nephew's wedding. He hates hospitals. He hates being sick. He hates the food. "They did all sorts of neurological tests," he tells me. "I don't want to go crazy. Some people with AIDS get demented. I don't want to do this. I don't want to be in and out of the hospital for years, in and out, I don't want that to happen." The phone rings; nurses, doctors, come in and out. Visitors come, visitors leave—a sustained conversation is impossible. We joke, between interruptions. "At least you won't have to worry about going bald." I run and buy food. We've decided on an elegant Italian dinner together. I race back, with take-out, oil dripping through the bag. I race back to Mike calling for help. "I am sick, very sick. Get the nurse. Get the bed pan, get the vomit pan." And the nurse and I scurry around, trying for ways to ease this body. And Mike's eyes are round, wild and dark. After a long time, I sit on the edge of the bed, and cradle his head and hold his hand. "This is awful," he says. He falls asleep. I make it all the way to the elevator before I cry. My friend, waiting at the end of the taxi ride, cradles my head and holds my hand.

MAY 14, 1986

I start writing letters to him. Letter after letter, suddenly there is so much to say. Yet, all my letters can't get further than:

Dear Mike,

I love you. I want you to know that. I wish I could make your fears, your pain, your whole illness go away.

They remain unsent. I call on the phone instead, getting the daily progress report, offering up my ears. Flying in to visit, desperately wishing our family had not flung itself all over the east coast, that we had remained all clustered together in one town, that visits could happen in between little league practice and school picnics.

MAY 27, 1986

I finally understand that I will weep my way through this. Sometimes it's the way. The only way.

I don't want him to die lonely.

MAY 29, 1986

I call every place I can think of. I call New York and Boston and Providence, trying to find support groups and information.

"It's a very fragile virus. 1 part bleach to 10 parts water kills the virus.

"There has been no known infection transmission from people living in the same household. Take precautions: wear rubber gloves when dealing with soiled laundry or body excretions. Do not share toothbrushes. As an added precaution, don't share dishes and silverware." [Phone conversation with American Red Cross volunteer—NYC 1986]

"So far we don't think that this can be spread by casual contact. Just tell your husband not to worry. Most likely it can't be spread that way. To be on the safe side, don't share laundry or dishes." [AIDS Action Committee Hot line—Boston 1986]

I go armed with information to Dave. "As far as we know," "most likely," "there has been no known,"—these are too vague for him. He tells me that they thought the blood supply was safe, until they found out otherwise.

I send information on support groups to Mike. Nothing exists closer than an hour from where he lives.

The stupid vacation looms.

We speak to doctor after doctor in the Boston area. They all start with the same hateful phrase: "As far as we know. . . ." They say, "there is absolutely nothing to worry about concerning living in the same house, having casual contact."

"SEE!" I scream. I have resorted to screaming. "Your fears are irrational."

"What if they're not irrational? What if I'm right?" he screams back. "All I want to do is talk about it, take precautions. I want the kids to know they shouldn't share toothbrushes, they should be extra careful."

Sounds reasonable.

"But," I say, "Mike has just found out he's dying. Nancy is reeling, and you want me to tell them *you're* afraid?"

JUNE 1986

Mike comes home from the hospital very thin. His skin is stretched like cellophane over his bones. In New York, the minute to hour to daily struggle of recovery is happening. Mike's legs ache, walking is difficult.

Thrush has invaded his mouth and throat, eating is difficult. Nancy rushes from work, to shepherding kids to the end of the school year functions, to organizing the camp preparations, all the while cooking savory meals that end in the garbage.

In Maine, my father is removing all the rocks from the field in front of his house, digging and piling, and carrying—a seventy-year-old man doing hard labor for twelve hours a day. Frank manages his store and prepares for the wedding. My nephew is pushing us along into the next generation rather faster than we expected. Frank is becoming a grandfather. And every night, without fail, Frank travels up the road and admires the rocks piling up on the side of my father's field. In Rhode Island, the days are filled with work, little league games, teacher conferences, and at night Dave and I fight it out, after the kids are asleep.

The news is full of AIDS. In some little town in Florida, mosquitos are suspected of spreading the virus. An article appears about the possibility of bed bugs in Africa carrying the virus. Children with AIDS are being hounded out of school systems. Other experts stress how difficult it is to catch from casual contact. Fear, they say, shouldn't take over.

Mike and Nancy are determined no one should know. I hate the silence, the fear, the stigma. How terrible to be dying—and to have to deal with it alone. If only they weren't so intent on keeping secrets, we could all talk, and maybe then we could deal rationally with Dave's fears.

If only people like Dave weren't so afraid, they would not be so intent on keeping secrets. Round and round.

JUNE 1986

I tell Nancy that Dave is afraid and wants to take precautions.

"This is why we wanted to keep it secret," she says before she hangs up on me.

"Now look what you've caused," I scream at Dave.

JUNE 7, 1986

Rage erupts. I am not sure this marriage will survive. Nancy won't talk to me. I am spitting at Dave.

JUNE 9, 1986

There are ways I imagine leaving this earth—but they are my ways—what are Mike's?

I'm afraid of being left alive, if I fail him.

JUNE 11, 1986

Last night Nancy would not talk to me. Tonight Nancy would not talk to me.

JUNE 15, 1986

Nancy still refused to come to the phone today. My brother, weak in voice and brain working slow, relays this to me, making excuses for her, hassled, frazzled, overworked.

JUNE 28, 1986

At Kevin's wedding, Nancy is barely civil to me and Mike looks bewildered and confused at her coldness. I feel the weight of unspoken knowledge between us. Dave is fine; I was afraid he'd show his fear, but he didn't.

JULY 1, 1986

Nancy is offered a job in the next state. Mike insists she take it, even though she'll only be home weekends. The kids are at camp. My father, believing that Mike could not, should not be alone, drives the long six-hour trip from Maine to New York and packs Mike up in the car and takes him to Maine.

Once there, he puts him in bed, and he feeds him beef. He buys the best beef. He buys ice cream and makes him shakes. He packs him in the car and takes him on outings. He talks of political events, and brings him tea and coffee and helps him into comfortable positions for napping, and helps him into comfortable positions for watching and sitting in the sun. He puts him on the lawnmower tractor and helps him drive down the meadow, so he can be outside and see the blueberry bushes, when his legs no longer can carry him. He cooks him breakfast and runs to Frank's store and brings back lunch. He cleans up after him and does not complain when the food goes uneaten. One afternoon, when Mike is napping, Frank finds our father crying alone, out in the garage. As a sister, the helplessness enraged

and depleted me, as a father it must have been like swallowing razor blades. He nurtured well. This should not surprise me. As a tiny girl, it was my father's side of the bed I went to when my stomach hurt in the middle of the night.

On the good days, Frank drives up the road and brings Mike to his store where Mike spends the mornings at the counter drinking coffee, eating donuts and chatting with all the town. The river flows right behind the store. Frank digs out old rods, and he and Mike fish for trout underneath the bridge with the other small boys. On really good days, Mike wants to help out and so Frank sets him up at the cash register and Mike calls me, a grin in his voice, and tells me how nice it is to be with people again, as he rings up orders.

JULY 11, 1986

I go visit. I have decided it's time for honesty. Let's get this all in the open and be done with it. I do not want to spend the rest of my time with Mike hiding and deceiving, with Nancy dripping ice.

"THE BASTARD. How dare he control. He's turned me into a leper. I don't want my kids near him. I don't want him fucking near my kids. My dying becomes his panic." We were driving. We were following my father's car, down dirt roads. My brother was pounding on the dash board, screaming, cursing.

I become paralyzed. I have never seen him like this. I had no idea. What have I done?

"Just tell him you'll divorce him. How can he walk away from me? How can he reject me?"

All day long, he goes on like this. Whatever I say, makes it worse.

"He's not rejecting you. He wants to be with you. He just wants us to take precautions. He's afraid."

"How dare he. How dare he!! He's evil to walk away from a dying man."

"He's not walking, Mike. He's not walking."

It falls on deaf ears.

Back at my father's house, I sit down next to Mike.

He leans toward me. "He has to pay for this. There must be a cost." He turns toward my father. "I don't want you to let him into this house. He's out of the family. OUT. His fears can't control me. I will not be controlled

by his fears. Don't let him in this house."

My poor father.

Mike turns to me. "You shouldn't be married to him. Leave him. How can you stay married to him when he does this to me? LEAVE HIM."

"Kick him out of the family." He turns to my father. "Don't let him in this house ever again."

"I won't do that, Mike," says my father.

"I need her, she's my sister. She's essential to my survival."

"Mike," I say softly, trying again. "He's only talking about not sharing bathrooms with the kids, that kind of thing."

Wild. His eyes are wild. "I will not worry about it. I refuse. I am not a leper."

JULY 14, 1986

Mike refuses my calls.

JULY 15, 1986

Nancy calls to tell me that I've hurt him beyond repair. That he will never recover from this. That he'll die faster, now.

I believe her.

JULY 18, 1986

Dear Mike,

I love you and the last thing I want to do is cause more hurt. I am sorry to have caused you such pain. Please know that was not what I'd intended . . .

I send letter after letter. Mike refuses my calls.

JULY 20, 1986

I think I hate Dave . . .

JULY 26, 1986

Mike refuses my calls. —Do you think you're perfect, do you think you've never hurt me, I want to rail at him, even if he is dying.

AUGUST 1, 1986

Dear Nancy and Mike,

I will say this over and over again. I love you and the kids. I am sorry. I can only repeat that I am here, offering help and love if you want it from me . . .

AUGUST 4, 1986

Dear Mike and Nancy,

I will come and visit—the children are always welcome and wanted . . .

AUGUST 6, 1986

I don't know how to get them back.

AUGUST 9, 1986

Yesterday, I talked with my father, and he felt that Mike would not last too much longer. Something I knew, and did not know, still can't really believe.

Today, I am remembering smiles. Images flash—Mike on the beach, talking, laughing. The sun is hot, but the air is cool and crisp. The wind surfers are in the ocean, putting on a show for us. The humidity must be zero. The cliffs, the sand dunes, rise high, behind us. The beach has few people. We've spread out our blankets, and sweat shirts, and suntan lotion, and newspapers. Six children between us. They are running, and digging, and planning, and playing elaborate fantasy games, and building cities out of drift wood. We have two coolers full of sandwiches, and beer, and juice, and peaches, and napkins.

This is luxury of the highest order. We are playing hooky. We are discussing relationships, his with Nancy, and mine with Dave. We are in tune. We are smoking, and no one is there to make us hide our cigarettes. We have brought treats to the beach and no one is complaining. No one is bored with the sun and the sand. We are in tune with our pleasures and our vices and we are playing.

We pile the kids into the car, shower, and drive to Provincetown for dinner. We drive along the dunes, through the late sunlight, with the Beach Boys playing full volume, and the kids giddy from surprise with such carefree adults.

The next day, our father is expected and we both get tense, and we both

start madly cleaning, and lecturing the children on quiet and decorum. We laugh—how silly we are, we say and scrub harder. How ridiculous to clean like this on vacation to please this man who will stay only twenty-four hours—and I vacuum and he dusts, and I do the bathrooms and he the kitchen, and he picks up the living room and I go through the bedrooms. We work fast and well together.

I don't remember a sour note. Can that be possible? The weather was incredible, the kids were happy and in heaven. Every night we ate root beer floats on the pier with the tar smell and the fishing boats and the moon making its strong light shadow on the water.

The year? 1983.

August 16, 1986

Mike walks into walls and drops glasses he forgets he is holding. He goes back into the hospital with toxoplasmosis. He almost refuses treatment. "I will not keep doing this." But the doctor persuades him and the recovery is swift.

August 21, 1986

Tonight's conversation was so strained; but at least Mike and Nancy agreed their kids can spend some time with us. It's a start. I am grateful.

August 29, 1986

I spent this past week with Mike and Nancy's kids, and my guys, and Dave, and some other friends. It was a world of many kids and few adults, of giggling and crabapple fights, and charades, and skits and mountain climbing and remember to close the refrigerator and dirty socks go in the dirty clothes bag not on the couch. And toward the end of the week Jennifer comes to me in tears and off we go to my bed and I hold her while she cries about how it isn't fair that people can have fun while her father is so sick, and why is he sick, and I want to have a good seventh grade, and I don't want to be alone, and if he dies I'll be alone and it's not fair, and why can't they make him better, and please tell me he isn't going to die. He isn't going to die, is he? Is he? I stroke her hair and hold her close.

SEPTEMBER 24, 1986

I am in retreat. Occasionally, I tell myself I must get out and interact with people taller than I, and who offer more feedback than the computer, and I make a flurry of lunch dates and think of applying for more teaching jobs.

And my brother is dying. It is not an awareness that ever leaves me for long. And he is so angry at me. He believes I've abandoned him.

Trying to make plans to visit Mike for the weekend and Dave wants our family to stay in a hotel. Mike says this visit means nothing to him, unless we all stay in his house. So I visit alone and stay with him. But he is angry and disappointed and says the hurt is more than he can bear. He no longer is able to trust me, and why can't I tell Dave to go to hell. Nancy barely talks to me. All of our kids are confused, because no one is supposed to talk about how ill he is or what he has. Stop, stop, I want to shout and have him hear. This is not how I want to say goodbye, this is not how I want it to end.

I understand, I say to Dave. I understand that fear is fear and taking a risk with our children, even if it is slight, may be more than you can or should do. I say this and then I find myself furious at Dave because he didn't wipe his crumbs from the counter and his feet smell and he rents dumb movies for the VCR.

SEPTEMBER 26, 1986

There once was a sister in her early thirties, struggling with career, three kids, husband, the meaning of life, and intermittent depression. Her brother, years older, is diagnosed with AIDS. This brother comforted her in the middle of the night, helped her escape the wrath of motherhood for transgressions like crayoning on her bedroom floor; and in later years, their kids around the same age, this brother became a friend, a peer, sitting by their dying mother, exploring marriage, work, parenthood, all of it. This brother, lest you think in dying he has been idealized, this brother occasionally tended toward self-centeredness, sometimes more concerned with appearances and things than necessary. This brother, however, brought light when he came.

One version: this sister abandoned this brother.

Another version: this sister was spineless, trying so hard to please, not to make anyone angry at her, she made everyone angry.

Another version: this sister, trying hard, tried to balance many needs. Pick a version.

OCTOBER, 1986

I do not know what was said by Frank or my father to Mike to help him forgive. I wrote over and over I'm sorry, I'm sorry. He had to struggle through anger and disappointment with them. All I could do was wait—hopefully.

It was not easy.

When anger ripped at our family, when we tore at each other, I did not recognize it as a phase, a storm that passes as we struggled with AIDS. I felt horror as I watched this family, heard this family spew words, ancient grievances, dividing us, instead of pulling together.

But that fall, as I sank under the weight of anger and blame and guilt and grief—and I could only see Dave through a haze of fury and contempt, Frank came. He closed up the store after hanging up the phone with me, and drove the miles from Maine to Rhode Island, and he held Dave and me up, so we could breathe a little freer.

And when my father, tired, drained, exhausted from caring for Mike during that summer, started to rant about Nancy and her job and how selfish, and how could she take a job so far from home, Frank and I were able to soothe and calm him so another rift wouldn't go too deep.

And it made me realize that though this family might not be perfect, that we might fail each other in ways we never dreamed of, there were enough of us—so that where one caused hurt, another soothed and together we might just be enough.

Mike began to talking to me again. really talking.

OCTOBER 18, 1986

I spent the weekend with Mike and family. A sad weekend. Perhaps that is all I should say. I have found even among my closest friends—that their eyes glaze over and their attention wanders—after all death is a conversation stopper. Except with these friends, I am not talking about death and dying— I am trying to find a way, exploring with them a way for me to keep working, and packing lunch boxes, and laughing at kids' jokes, while my brother is . . .

NOVEMBER 1986

Mike is back at work. Nancy is back at work. The kids are all back in school. There is a period of relative calm.

Mike and I have long conversations about people's reactions as he begins to let friends know for sure, what they have long suspected. Most are more loving and giving than he'd expected. Most also have ideas about how this last phase should go. Sometimes he laughs and sometimes he is so amazed at the gulf between him and everyone else.

NOVEMBER 30, 1986

Death is no stranger to me. When my mother died—I was numb for weeks, with the pain of her death. And numb for months with the pain of her life. And numb for years with the pain of our mis-relationship. I could not let her life go unremarked. After she died I wore her clothes, and put up her picture on our picture board, and kept all the furniture and things she had made. She would not be forgotten.

A squirrel lies mangled in the road—I swerve not to mangle it more. My eyes tear. That such a world has grown up and around these squirrels—full of cement and fast moving vehicles that they have not fully learned to live with. Only die by. There are many squirrels—they are not an endangered species. I count seven dead on my mile-ride home.

DECEMBER 7, 1986

Mike tells me: "I want to shout from the roof tops what is happening to me. I sit in business meetings and I want to say—are you all nuts? I am dying. But I don't want my wife and children to think I am maudlin, I want them still to be around me."

DECEMBER 18, 1986

Who will Frank have to remember his childhood with, when Mike dies?

JANUARY–MARCH 1987

Winter to Spring of '87 was spent in bewildering crises. Up, down. Up, down. AIDS is a disease full of diseases—the numbers are staggering; the names are confusing. Mike was being assaulted and folded in on himself,

fighting a haze of pain and new pains. He could no longer work and his days were spent more and more in sleep, or watching talk show after talk show. It was hard to eat, hard to sleep, hard to walk, hard even to talk. Nancy stopped working and spent her days/nights caring, valiantly trying to keep a sense of normalcy going for the kids, while she watched Mike and their life together wither.

It is hard to believe families ever chose to live apart.

Nancy told me I caused everything to go bad, to change. I told her that it was AIDS killing my brother and changing things, not me, and I was sinking under the burden of guilt and blame. Yelling and talking, we cleared away the debris so we could come together and hold each other up.

Mike got on AZT.

Mike couldn't tolerate AZT.

My father drove from Maine to New York to Maine and back, over and over again.

My brother Frank drove on alternating days from Maine to New York and back and back.

I traveled from Rhode Island to New York to Rhode Island to New York over and over.

Families who move farther than twenty minutes traveling distance from each other are stupid.

We compared trips—he looks good, he's gained some weight, he lost weight, he seemed so happy, he seemed so sad. Maybe the AZT will work.

Mike kept repeating to me, "100% fatality. 100%." And then he said, "Someone's got to be the first to make it. Maybe me." It became a chorus we echoed, we held on to.

"I'm not finished," he said. "The kids are too young. Nancy . . ."

MAY 1987

After an evening with his kids at the dinner table he weeps. "I can't follow the conversation, it all went by too fast."

I sit with Mike and two of his close friends in the house in New York. He speaks slowly, the time between thinking and forming words is growing longer. He speaks of being weary, of being cold, of being despairing, of being weary and cold and lonely and feeling apart.

They talk loudly, quickly, with big movements of their healthy bodies.

They talk of business they used to have in common, and grow impatient as Mike loses interest.

You should get out more.

You should fight this, fight it hard. Don't give in.

You should take pleasure in the trees beginning to bud, and the daffodils poking through.

You should laugh more.

Mike nods.

I hate their list. Even when dying we have to worry about other people's expectations?

I remember, then, the conversation Mike and I had about telling the kids how sick he is. "You should tell them—give them a chance to have their own feelings."

We all have our shoulds. As if there is a wrong or right way to be dying—a good, successful way or a bad, failing way.

JUNE 1987

The phone calls keep flying. Mike is not often coming to the phone, he finds it too tiring to try and understand.

"I plan to sit in the car, with the garage door closed, turning on the engine, letting the exhaust do its work," he tells me.

"No," I say. "Not that way—too hard on the kids, on Nancy. I promise, I will find you a way out if you need it."

"Really? Would you really do that for me?"

"Yes."

JULY 4, 1987

The call comes. Mike is back in the hospital with pneumonia.

When Mike went into the hospital for what was the last time, though of course we did not know it was the last time, although we knew it was the last time—my father was visiting his wife's relatives out west. I didn't know what to tell him when I called. A month before I had called him home from another trip to Atlanta, and by the time he got here, the crisis was over.

I called.

I don't know what I should do, he said.

Come, I said.

I'll drive, he said.

Fly, I said.

What airport? he asked.

Either one, I said.

Who will pick me up?

Take a cab from the airport.

I knew what was happening. My father's brain stopped working. I understood that. When faced with knowledge like this, the brain can't work. What could work?

I remember a similar conversation with my brother, when my mother lay dying. It looked like it would be soon and we called. I don't know what to do.

Come now, I said. Drive carefully, but come now. People need sometimes to be told what to do. I wanted someone to tell me what to do—but everyone was very busy.

In the dark part of the night, Mike started making awful, terrible choking sounds. I was in the room half asleep, wanting to sleep, feeling just as I had when the babies were tiny and woke up to be fed. Not now, I thought, wait a little. I came fully awake and called the nurse and held his hand, and she came and stuck a tube down into his lungs and suctioned. She must have known this was it. But I didn't. I didn't know he was drowning. I felt good. See, look, I've helped him. I woke in the middle of the night and saw him in trouble and helped him and now he will be okay till the morning. I rubbed his head and held his hand till he fell asleep and I went back to my chair and blanket, feeling relief. Those terrible gasping noises woke me again. And this time I knew exactly what to do and I called the nurse and told her what was needed. And she came.

I went to the lounge. The coke machines were lit. The TV was on. No one was there. I went back into the room, as the nurse was just finishing. The room was dark, except for the working light, and Mike was sleeping, eyes closed at least, and the terrible sounds in his throat were less, if not gone. And the nurse said: I think you should call his wife. And I asked, Now?

I ran to the pay phones to call Nancy and got no answer. I trembled and dialed, I shivered and dialed I let it ring and ring. And got no answer. I

went back into Mike's room and kept calling from there. No go. I frantically dialed and called and dialed. The nurse came in—"I am going to give him morphine now," she said very quietly, "to ease his breathing." I knew what that meant. Mike and I had already watched my mother die. With the ringing, unanswered phone in my hand, with the hospital dark and quiet, except for the hissing machines, with Mike on the bed, eyes closed, working so hard to breathe, with the nurse standing on the other side, looking gentle and warm, I panicked. "What do I do?"

And she told me. "Hold his hand. Talk to him. Tell him you are here."

"His wife. I can't reach his wife."

"Hold his hand."

And so I held his hand with mine. I dialed that phone, and put it down letting it ring and ring, checking occasionally to see if Nancy would pick up. The hospital stayed dark and quiet. I held his hand and smoothed his forehead and murmured to him. I can't remember what I said during those hours. By the time Nancy picked up the phone, I was calm.

That nurse told me what to do and I will always be grateful. Nancy arrived as the light began to come and the city below began to be noisy with car horns and the hospital started to wake up. And the rest of the day, while Mike lay in a coma, another part of me took over. I called funeral homes who would take AIDS patients, and called my older brother Frank to get Mike's children and come quickly to New York, and reached my father and told him it's okay to drive—and then greeted Frank and the kids, and went with Frank to the funeral home, and filled out forms and answered questions about my brother who was dying.

At one moment that last week in the hospital, he told me "I'm so scared."

I wish that last week I had woven stories for him in the air. I wish I could have lulled him to peace.

I held his hand. I stroked his forehead. I massaged his shoulder.

"That feels good," he said.

What? Which? This? Wanting to know exactly what movement felt good so I could do it forever.

I sang no songs and did not weave stories in the air. All year I had wished to be a joker. If only I was a person who told jokes, who could entertain with light banter.

I was filled with a silence of helplessness so great I heard echoes in my ears.

He had not reached acceptance. He had not come to terms. And he was going to die anyway.

There was no comfort I could give.

The night before he died, he asked me, "Is it okay if I stop trying to live? I've tried so hard."

This was not acceptance. It was defeat. The pain and struggle had worn him out.

When he died, when he breathed his last breath, his mouth stayed open, and all the color drained from his body. I understood, with great and sudden clarity, the meaning of the word "life" because once it is gone, all that is left is a body. When he died, when he breathed his last breath, a large NO rose from my gut. I had known this was the outcome for over a year. In the past weeks, we knew it would be soon. In the past days, I knew it could happen at any moment. For the past few hours, it was simply a matter of time. And still, this NO rose from within, in a great wrenching cry. And with it rage.

Not anger, not fury, RAGE. How dare he leave me to deal with, to come to terms with, to understand his death, without him.

A year ago, he had screamed at me, in a moment of hurt and rage, when he thought I was abandoning him, "You are essential to my survival."

Well, I wanted to shout to him now, it goes both ways. And look who abandoned whom.

SEPTEMBER 1987

There was a great disturbance in the spin of the earth when Mike died. Simple walking has become a trick of balance.

JANUARY 1988

These past months, I have listened to regrets.

My father's voice: I should have stayed there. I should have known he was going to die, I should never have gone back out west. I should have been with him.

Nancy: If only I had known, if only I had not had the air conditioner on that night, if only I had heard the phone . . .

And I say: If only what? If we had all done what we were supposed to do—according to our own list of supposed to's—would it have made a

happy ending? Would it have changed a thing? Would it take away his death—or our pain?

MARCH 7, 1988

It's a spring day. The windows are open and the caw of crows, and voices of walkers are loud as they pass under the window. There is silence in the house. Kids are at school and Dave is at work.

Today I remembered that Mike taught me the cha cha. I remembered our living room in Baldwin, with the large front windows filled with colored glass bottles. Those bottles, the fact that mom liked them, always gave us a possibility when it was time to buy birthday and mother's day gifts. The windows were actually out on what we called the porch. Originally it must have been a porch, but with various alterations, it was now filled with plants and large windows and was part of the living room. And in this living room, my brother, older by many years, lifetimes, or light years it must have seemed then, though by the time he died, the nine years age difference had shrunk to nothing—this older brother, taught me to dance. The cha cha. Stepping and swirling, laughing—with pleasure and anticipation of my own high school years ten years away. Of course, ten years later, there was no such thing as dancing the cha cha in high school gyms.

So these memories, coming at unexpected times, in the middle of dusting, or making doctors' appointments for the kids, or straightening the pillows on the couch, are like cramps, sudden, fierce, doubling me over—forcing me to clench my jaw. It's been almost a year.

JUNE 13, 1988

The AIDS QUILT is coming to Boston. I want Mike's name in there. I want to do a patch. They have 15,000 patches. I will ask Nancy to help me. Naming. Names are very important. Why does it seem possible that it might hurt less if Mike's name was there. Mike—just writing it out—hurts so god damn much.

I want to see him, and talk to him and tell him that I'm trying to quit smoking, and that our family craziness is written in a book I just read, and laugh with him—and be proud of our kids together, and sigh indulgently over our respectively nutty spouses. I want to tell him that I miss him more than I miss smoking—and I know he will understand just how great that

kind of missing is—as crazy as it sounds to anyone else. I want to talk to him about buying that place together in Vermont. The big old farmhouse, with slanting floors, and wide planked floor, with the barn attached, and many additions made over hundreds of years, overlooking fields in front, that fall away into a beautiful mountain view. To the side of the house is a small stream with a large pond. On the north side of the house are the woods. Deep and dark. Mike paints the house white with green shutters because that is traditional New England. And it's big enough for both our families to be in it at once—and so we can share.

This is the family home that our children bring their children to. Mike and I will sit on the front porch, overlooking the mountain view and smelling the long, hot grass. Nancy will be in the kitchen, cooking up a storm—because she loves to cook. Dave will have shopped, buying all the food for the weekend after hours of super marketing—because he loves to shop. Now he will be organizing, out back in the shade, round robin badminton tournaments. Soon he will come to where Mike and I are rocking with our feet up on the porch railing and insist we come play. Mike and I talk continuously. We have cleaned all afternoon and have sprinkled vases with wild flowers all through the house. There is fresh wood laid by the fireplace for the evening after the sun sets and the night gets cool and we gather to play poker or some game or other. I have the feeling that our grown kids will want to play charades in remembrance of gatherings past—when they were little and we vacationed in a succession of rented or borrowed homes.

And Mike and I, with all this around us, marvel. We are discussing how it could have come to pass, how wonderful that we have held together the family, how terrible this one or that one is for not appreciating it more. Our personal everyday lives will intrude little on this conversation. Our beings are immersed for a time in family, past and present, as we remember parents and childhood. While we speak, Frank comes up the road.

This brother pretends not to care for all this family togetherness—and always he comes. Dave's voice from the back is insistent now, as screams and battles emerge over the badminton games. We go to check it out. Nancy joins us, challenging her older son Chris to a match.

And for some sweet moments, we again wonder at our blessings. That we could come and be here like this, all of us. That all those emotional upheavals, all those struggles of earlier years, have brought us all together, generations of us—for moments of peace.

Of course, this is not to be. We didn't quite make it together through all those emotional upheavals and struggles of our earlier years. Mike died.