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This Is How It Happened

March 8, 1998

Dying of cancer can make you feel very popular. Everyone you know—practically everyone you’ve ever met who had any strong feelings about you in any way—feels the need to come and see you one last time. You are Mecca. You are the Wailing Wall.

I was diagnosed with Stage IV squamous cell lung cancer five months ago, and since then I have entertained—for lack of a better word—a steady stream of visitors. Today it was two former work colleagues, Marguerite and Betty. My youngest child, Emma, who just turned 30 and seems to think this makes her ancient, was here when they arrived. One of my children is always here when I have visitors, as though they think I need a bodyguard or a valet. I’m not sure why.

Unless the visitor is one of my closest friends or immediate family, visits always follow a remarkably similar pattern. First there is the forced jovial greeting—a hale and hearty “Well, hey there. You look great.” This is followed by a moment of awkward silence. Marguerite and Betty were no exception. Emma let them into my apartment and both immediately descended upon me. Marguerite got to me first. She’s younger than Betty and moves faster.

“Shelley!” she said, going in for what looked like a bear hug, but which was clearly aborted when she got about six inches away.

“You’re not going to break me if you hug me,” I said. I’ve lost a lot of weight and know I look much more frail than I used to. I had stood up when they arrived, but I’m not always steady

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on my feet. I got two gentle hugs, one from Marguerite and one from Betty. Then we all sat down—me in my standard spot at the end of the couch, Betty in the easy chair across from me, and Marguerite in the booby prize seat—sharing the couch with the cancer patient. Emma hovered on the sidelines like a border collie watching its flock, watching and waiting to fix anything that needed fixing.

Marguerite and Betty did the “Hey, you look great” thing, and then came the next predictable moment. Betty asked, “How are you?” This question is always asked in the most sincere manner possible, and I know everyone who asks it is sincere and well-meaning, I’m just never sure how to respond.

“Fine,” I replied. Generally all I can say is “Fine.” Considering I have I cancer, I am fine. I don’t feel cancerous. I don’t feel particularly bad or sick. I just feel weak.

“That’s good,” Betty said, and I know she meant to say more but didn’t have the words. She is a kind soul.

“You know,” Marguerite said, “everybody down at school misses you. They all send their best.” Marguerite, Betty, and I used to work together at the local state university until I retired last year. I wasn’t more than a glorified office manager there, but the job saved my life years ago when my husband moved out and I still kids at home. I liked the people I worked with, and they liked me. Many of them have sent cards of support or telephoned. A brave few, like Marguerite and Betty, have made the journey to visit the dying.

Perhaps they aren’t brave at all. Perhaps they drew the short straw when the old gang decided that someone had to come and visit. I know that I make some people uncomfortable now, but let’s face it, we’re all dying. Some of us are just going about it faster than others.

“You know,” Marguerite said, “my uncle was diagnosed with prostate cancer four years ago, but they caught it and zapped it out of him. He beat it. You’ll beat this too,” she added with startling surety.

“She’s right,” Betty said. “You’ll beat this, you’re strong,” Betty said.

“Thank you,” I said. I didn’t want to be rude, so I didn’t tell them the truth. I won’t beat this. That is the unfortunate fact of my existence. It’s too late to zap it out of me—it was too late to zap when they discovered I had cancer, and even so, they zapped for a couple weeks anyway. I think the doctors just wanted to feel they were doing something. At first, I wanted them to do something, but their zapping didn’t seem to have any appreciable effect on my tumors. It did, however, cause my hair to fall out and actually make me feel so sick that I finally could believe I was dying. That’s when I decided enough was enough—no more zapping.

Don’t get me wrong—I’m not giving up. I love living. I have had a good life and desperately wish for more of it. But not as a cancer patient. Not taking treatments that make me so weak and sick that I don’t feel I’m living.

Betty and Marguerite stayed a little while longer, then made a polite exit. It was good to see them, but my stamina for socializing isn’t what it used to be. Emma let them out while I made my way to my bedroom for a nap. Emma came in and sat down on the bed next to me.

“Do you want me to stay while you sleep?” she asked.

“No, that’s okay. You go home and take care of that nice husband of yours.” Emma was married a little less than two years ago to a lovely man named Aaron. I know I’m leaving her in good hands.

“I hate leaving you.”

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“I’ll see you tomorrow.” Her face looked unsure. “I’ll be here tomorrow,” I said. “I’m not going anywhere.” Emma’s face screwed up slightly in the same expression she would get when she was a tiny girl and would get frustrated. “What’s wrong?” I asked.

“I don’t like thinking about the day when you won’t be here,” she said.

“I know,” I replied.

“Are you afraid? Of dying?” she added, as though she wasn’t sure if she was allowed to actually say the word. This is something I have thought long and hard about, and I can honestly say that I don’t think I am. And I told her so. “What’s it like?” she asked. “I mean, what goes through your mind? Do you think about it all the time? Do you still think about mundane things like ‘I have to do the laundry’ or ‘I should call so-and-so?’ I just can’t imagine...” She paused. “I just... I’m scared, Mom.”

“You don’t need to be scared for me or for you. You’ll be okay.” Even as I tried to reassure my youngest child that she would survive my passing, I thought back to when I lost my own mother, who died far too young. All I can remember from that time period is devastation. That’s when I decided to start taking notes, to chronicle what I’m going through and what I’m feeling. Perhaps it will save my own children from devastation.

March 9, 1998

My cancer started in my lungs. I’ve never smoked, but one of the wonderful ironies of being an organic life form is that you don’t need to smoke in order to get lung cancer. I don’t cough any more than the next person, and chest x-rays are not typically on the list of annual physical exam items. By the time they found it, it was too late to zap it out. It’s funny, when I say this, I feel as though I’m making excuses, as though it’s somehow my own fault that I have

cancer. But there is no blame lurking in the wings waiting to be assigned. Things, despite our very best efforts to prevent them doing so, happen.

I liken cancer cells to a very persistent band of evangelical missionaries. They move in with a single purpose—to increase their numbers. Using my lungs as a base, they have thus far converted my pancreas, my liver, and my brain. I don't mind the pancreas and liver so much—I never thought much of those organs anyway. I am, however, disappointed in my brain. It's served me well over the years, and I suppose I expected more from it.

Sometimes I feel bad when visitors show up because I don't have any great insights to offer them on the nature of human mortality, and I think they're looking for something—some word of wisdom. Every meeting is fraught with the knowledge that it may well be the last time they ever see me. I'd really like to say something profound, something that the person can look back on years from now and say "You know, the last thing Shelley ever said to me was..." I think I disappoint, as my thoughts are primarily occupied with more immediate issues: Will my bowels move today? Will it be terribly painful if they do? Will I feel well enough to eat something? How many calories will my children attempt to push down my throat today? Can I make my body move in the right way at the right time to get to the bathroom before I pee all over myself? This is more than enough to occupy anyone's day. Contemplating the issue of my own mortality just doesn't fit in.

I did spend a lot of time thinking about death when I was first diagnosed. At first I couldn't believe it. It was the quintessential surreal moment when you're positive you must be dreaming. But it's five months later and I haven't woken up, so I can only assume this is my real, waking life. It's there and I've accepted it: I'm going to die. This is inevitable, and I will not waste my last precious days worrying about something I can't change. I may not have any

insightful, profound thoughts on the nature of death and dying, but I like to think that I'm at least setting a good example for what to do when you are dying.

March 10, 1998

My children are accepting my illness with varying degrees of maturity, anger, sadness, and efficiency. My oldest, Janie, is taking over. Although I'm still living in my apartment—the second floor of a garden apartment complex where I've been happily ensconced for over ten years—she's made a schedule for all my visitors. They must now call ahead and make an appointment. When I tell her I feel like a trendy New York restaurant, she doesn't laugh. She does have a marvelous sense of humor—really, she does. She has a Ph.D. in anthropology and I think my illness has thrown her for a loop—it's the first thing in her life she hasn't been able to fix by sheer will or native intelligence. Her husband, Jason, helps keep her in balance. He's been part of the family for so long, I feel as though he's my second son.

My actual son, Jerry, seems to swing back and forth between his standard laid-back, semi-ambivalent exterior facade and an interior of mush. He waits until even his wife, Beth, is out of the room before he shows the mush. Then he cries and tells me how much he loves me and how brave he thinks I am. When I tell him I don't feel particularly brave—this is simply something I have to go through—he says facing the unknown and not running away is the definition of courage. He seems to believe that I have somewhere to run. I feel privileged that he shares his fears with me. I suspect that he shares them with Beth too. Somehow she understands and accepts these two divergent sides of his personality. He's lucky to have found her.

Karen is my next child. She's the only one of my kids who isn't married. When she was younger, she liked to pretend that her family—especially me—was unaware that she prefers women to men. When she turned 30, I finally said to her that she didn't have to pretend. I don't

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know why she felt she couldn't, I believe the term is "come out," to me. But she couldn't, so I'm glad I said it—it did bring us closer. She ended a long-term relationship shortly before I was diagnosed and thus isn't sharing my illness with anyone. I'd like for her to have someone to lean on.

And then there's my baby, Emma. I'm not sure how we managed it, but sometime in her late teens, we became friends. I am still her mother and she still (occasionally) acts like a daughter, but we're friends. Although she is my youngest, I often feel she's the one I need to worry about the least. As my former father-in-law always said about Emma: She's got her head on straight.

These are the people I'm leaving behind.

There is a former husband in the mix too. Jack. I'm not sure how to describe him. How do you objectively describe the love of your life who broke your heart? We've been divorced for 16 years? 17 years? Long enough to forget the exact amount of time. I've accepted the divorce, his infidelity, my life without him. In fact, I've loved my life without him. He isn't a part of my current life, but he is a part of my past. He's the father of my four wonderful children, grandfather to three beautiful grandchildren. For that role alone, I have to mention his name. I suppose I'm leaving him too.

March 15, 1998

Jack came to see me today. This was his first visit to me since I was diagnosed. Really, his first visit to me ever. We've seen each other at weddings, funerals, and occasionally at birthday parties for the grandchildren, but this is the first time he's paid me a social call, if you can call visiting your ex-spouse who's dying of cancer a social call.

I opened the apartment door to and saw Jack standing there with this little grin in which only half his mouth moves. It used to make me melt, but I'm proud to say it hasn't had any distinguishable affect on me for years. "Hi, Shel," he said. "Sorry I didn't call first, but I wasn't sure if you'd want to see me."

"Why do you say that?" Even as I said this, I realized it was a loaded question, because there are so many answers to it that are just downright nasty. I figured he was old enough to know to close the apartment door behind him and headed back towards the couch to sit down. Even with a quad cane, at this point standing up for too long is difficult. Out of the corner of my eye, I saw him move toward me, as though he wasn't sure whether I needed help walking or not. It was a sweet if awkward gesture. Funny how I used to think he was so smooth.

"There's a lot of reasons you might not want to see me," he said.

"Don't I know it," I answered. I know he caught the glint in my eye because he just gave me another one of those Jack grins and mumbled something about everybody making mistakes.

He hung around the entrance hall for a second, so I told him to come in and sit down. My apartment is not large, but for a moment, he looked very small and far away standing there by my front door. He walked over to the couch where I had managed to plop down. He was still looking nervous and ill at ease, then at the last instant chose to sit in the easy chair opposite me. That was when I realized the visit was not about me, but about him. It was actually a relief. I don't like visits about me. I feel put on display. People want something—wisdom, insight, comfort—that I don't feel equipped to give. But Jack, Jack I can handle. I'm over losing him. If he needs forgiveness, that I can give.

We started out with the safe topics: How are you feeling? Which of the kids have you spoken to lately? □ Which grandchild did or said what adorable thing? Then there was a pause. My children have always referred to it as the 20-minute lull. Supposedly, approximately every 20

minutes there is a lull in every conversation—that moment where the conversation dies down and people either start a new topic or decide to grab their coat and go home.

Jack looked at me and smiled a half-hearted what-do-I-do-now? kind of smile. Then his expression changed. “The 20-minute lull,” he said triumphantly.

“I forgot you were around when the kids started espousing that theory.”

“I was around. It was Janie’s freshman year in college.

“I seem to remember her timing the conversation at the dinner table,” I said.

“Remember how after one semester at college she kept spouting off every theory she had heard like it was the gospel truth? She was so intense and serious about everything, and she treated you and me like we were morons.”

“I didn’t realize you had noticed that.”

“How do you not notice your daughter treating you like you’re the village idiot?” he said, picking a scented candle off the coffee table and sniffing it. The candle was a recent gift from a friend. It’s an aromatherapy candle. The fragrance, when lit, is supposed to soothe and relax. I suppose that’s a handy thing to have around. “Have you noticed that all our daughters start thinking we’re stupid the minute they begin college?” Jack added.

“Just our daughters?” I said. “I think they all thought we were stupid before they started college. Teenagers are surly. It comes with the territory.”

He put the candle down. “You weren’t.”

“That’s true,” I said with mock coyness. “I was always the nice girl.”

“You still are,” Jack said, with no trace of coyness or mock anything. “You still are the nice girl.”

Well. Wasn’t that sweet? If I didn’t know better, I would have thought he was flirting with me, but I know what I look like these days. I’ve decided that one of the symptoms of a

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terminal illness is forced androgyny. It's not just the weight loss or sunken eyes or hair loss that makes your appearance start melding gender lines—it's the way you're viewed by the rest of the world. One morning you wake up and you've moved beyond female or male and become a third, genderless gender. I don't think I look male or female anymore—just human.

“Thank you,” I said.

Jack kind of shrugged in a ‘it's-the-least-I-can-do’ way. “Well,” he said, standing up. “I suppose I should be going. I don't want to tire you out. I'm sure you need to rest.”

“Thank you for stopping by. It was good to see you.”

I stood up, a little faster than I should have; my head started spinning the instant I was vertical. I think I must have started swaying because Jack quickly took my scrawny arms in his hands. “Are you okay?”

“Sure,” I replied. I was momentarily embarrassed to let him see how weak I had become, but that moment passed.

“I can see myself out,” Jack said, and gently helped me sit back down.

“Well, considering the circumstances, I won't stand on ceremony,” I replied. “In fact, I won't stand at all.”

He gave me a little smile. It was a tired, sad smile. “Considering the circumstances, you have been the perfect hostess.”

“Thank you.”

“Um, do you need anything before I go? A cup of tea, juice, something?”

“No, that's okay.” He paused as though he was going to say something else. “What is it?” I asked.

He looked at me and his face was wide open, like I hadn't seen it in years. “I love you, Shel. Always have.”

A part of me had actually wanted this—or something like it. Some sign that this man who had been my husband hadn't wasted 25 years of my life in a marriage that meant nothing, that my children had been conceived out of love rather than obligation, and that ultimately some small part of my ego could be vindicated. But another part of me didn't want to shed a tear in front of Jack.

“Likewise,” I said. That was all I could manage.

He ran a hand through his hair as though he was trying to gather up the nerve to say something else, but all he said was “I'll see you,” and that was it. That was our visit. But it was enough.

March 21

I'm moving. Or rather, I'm being moved. This apartment is getting to be too much for me. I hate to admit it, but I need help. The tumors on my brain have affected my motor skills—I can tell myself to stand up and walk to the kitchen or the bathroom and it simply doesn't happen. Sometimes I forget what to do with food once it's in my mouth. The other day, in one of my few solitary moments, I nearly choked on a piece of toast because I couldn't remember how to swallow. I knew I had to swallow, that the food wasn't supposed to stay in my mouth all day, but I couldn't quite remember how to get it out of there. The lack of reliable motor skills brings up other issues too. Getting to the bathroom is difficult. I realize I keep harping on this, but it's become an issue. I'm not incontinent. I am not unaware of when I need to go, but I can't always make my legs walk where they're supposed to when I need them to. I can't keep both the apartment and my dignity—one of them has to go.

March 23

I've moved. I'm at Hospice House. It's a very nice facility—clean and modern yet cozy, set on about five acres of land so every room has a beautiful view. And I'm not the only one sitting around in a wheelchair, which is somewhat refreshing.

Janie and Karen moved me in. They packed for me—rather, I sat on the bed and told them what I wanted to bring. This move wasn't like any other in my life. Just about all my possessions are still in my apartment. I'm only bringing with me what I truly need—some photos, some books, some clothes. I read once, many years ago, that Mother Theresa could carry everything she owned in one bag. She had reduced her material possessions to the absolute necessities. At the time, I couldn't comprehend owning so little. Now I wonder how I ever accumulated so much.

We don't say, although we all know, that I am going to the hospice facility to die. It's like moving into a very exclusive co-op—except in this case, the only criteria for admittance is that your doctor must agree that you have less than six months to live. In all honesty, I know that I have much less than that. I haven't told anyone this—they'd think I was being pessimistic or morbid or giving up. I'm not. I just know that I can't keep this up much longer. My body is breaking. I've resisted the idea of moving to the hospice facility because I want my independence and my space. So many choices have been taken from me; I don't have many left. The choices I am still allowed to make for myself I will hold on to.

My daughters and I pretended that I was packing for an extended vacation. My children seem to be pretending a lot—that I am still who I was, that I will be around for a long while yet, that miracles are possible and that I deserve one. I don't think any of them are in actual denial: they understand that I am dying, they're just getting used to the idea in incremental fashion.

I thought the point of moving me to the hospice facility was so that I would have professional care 24 hours a day, and yet my children won't leave me alone. One of them is almost always here. I adore them—I adore listening to them, seeing them, holding their hand, even simply breathing in the same room with them. But I miss my privacy and my independence. I don't think I've slept more than four hours at a stretch since I got here, since a nurse or an aide is always checking in on me. Not that they need to, because one of my kids is almost always here. Don't these people realize that I'm sick? I need rest.

April 5

While my personal decision-making has been reduced in quantity, I accept the fact that it remains strong in quality. There really are only a few things about which I can even make decisions at this point. I can still choose what and when I want to eat and drink. I can still choose when I want to sleep. I can choose when—more or less—I want to die. And I can choose who—if anyone—I wish to have present at the moment of my death.

These last two decisions are not to be taken lightly. Knowing my kids, they'll try to read all sorts of things into the day I choose. Easter is coming—or maybe it's already been. I have become forgetful. Easter might have been an appropriate day. There is an Easter basket in my room. I thought it was a flower arrangement, but when I focused on it, I could see it clearly. An Easter basket. It must have come early this year. So it won't be Easter. I know that none of my children or grandchildren have birthdays in April. I can remember that and that is important. I would not die on, or near, any of their birthdays. That isn't fair. Somebody was born in May—a grandchild? Kaitlin. Yes, Janie's oldest, Kaitlin, was born in May. The end of the month, I think. May is out. So I will die in April.

I had considered trying to hold out until June, until my ex-husband's and my wedding anniversary. I thought that would have been an amusing final touch, but decided it was too mean-spirited. And I know I couldn't make it to June. I'm tired. This has been a long journey. Fortunately, nobody gives me the "Rah Rah Rah" football banter anymore. It is quite obvious to even a casual observer that I won't be around much longer.

So the date—more or less—is decided. The more important question is: who will be with me?

April 10

I'd like to think I'll face the moment of my death courageously. The problem I think most of us have regarding death is that we fear pain. We fear that death will be painful. Therefore we fear death. The hospice will not do anything to keep me from dying when I'm in the process of doing so. They will, however, work to keep me as pain-free as possible. If this is true, then I have nothing to fear. And truly, I'm not afraid.

I believe in God. Not because someone at school or at church told me that I should. I believe in God as I believe that I need to take another breath in order to stay alive. To me, the presence of the divine simply is. I'm curious to know what the divine is. I think I shall soon have my chance to find out.

When I think about who I want to be with me at the moment I cease to be, I have a number of options. There are plenty of nurses and social workers running around, some of whom I've grown quite fond of. There are friends who visit regularly. But somehow none of these people seem right. This—dying—will be my last act in this life. It's too intimate a gift to give to someone who isn't flesh of my flesh, blood of my blood.

But which child? I have to rule out Emma. They will pump me as full of drugs as possible so that I will not feel the pain—whatever pain may be present. But I don't know what will happen. It could be ugly. I know I've said that I don't have to worry about Emma, but I don't want her to watch me die. She is and always will be my youngest, my baby. Therefore, Emma is out.

Jerry would like to pretend that he's a stoic man's man, but I know how deep his soul goes. I wouldn't put him through it. Thus Jerry is out.

Karen... maybe—if she had someone to hold her hand. A significant other to put an arm around her and ask “Are you okay, sweetie?” I don't care whether that someone is male or female. I'd just like to leave her with a source of unconditional love. To the best of my knowledge, she is alone. And I won't make any child of mine go through this alone. So Karen is out.

Janie would seem the logical choice to be with me—there's a certain symmetry about having my oldest child present, plus she's pragmatic and level-headed. And yet... something tells me that the efficient, grown-up front she's putting on is just that—a front. She has always willingly shouldered any responsibility asked of her without complaint. That is one of her finest qualities and one of her worst. I'm never sure if I'm asking my oldest child to do something she truly doesn't want to do. This time, she should be relieved of the responsibility of being the oldest. And thus Janie is out.

That's it. I don't have any other children and I'm not going to die in front of my grandchildren. And I sure as hell am not dying in front of my ex-husband. It looks like it's me, myself, and I.

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Here we are again. Another day. When Jerry and Beth came to visit this morning, he asked how I was. I told him, “Despite the catheter in my bladder, my inability to feed myself, and a sharp pain anytime anyone tries to move me out of my bed, today is a gift. I’m still alive.” Jerry replied that “All this time, I thought the hearing was the last thing to go, and now it turns out it’s really sarcasm.” I love having my son make me laugh.

April 13

I can’t escape the notion that because we come into this world alone, possibly we should leave it in the same manner.

April 14

My children watch me while I’m sleeping. They watch me breathe. I think they want to reassure themselves that I am still breathing and have not—yet —died.

April 15

I’m starting think that it’s time for me to go. I don’t feel like eating or drinking anymore. I don’t feel like talking. I don’t want to get out of bed. I’m starting to think there really isn’t a point to staying here much longer.

April 16

I haven’t spoken since yesterday. I haven’t eaten or drunk anything since yesterday either. At least I think it was yesterday. I haven’t felt much like speaking, but Jerry was right. The hearing really is the last to go. I can still hear them talking about me, the hushed tones from the other side of the room: How much longer do you think she has, Janie? What does the nurse

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think? What does the doctor think? How much longer? When do you think it will happen?

Should we spend the night here? My dear, sweet children, it will happen soon. I'm too tired to open my eyes at this point, but I can hear in their voices how worried they are. I hate doing this to them. If I could hasten this process at all—essentially, if I could die faster—I would.

April 17

My own mother died quietly in her sleep. I'd like to die in my sleep, except I don't know that I really sleep anymore. You know the feeling you get on a Sunday morning, when you know you're going to the late mass and you don't have to get out of bed for another half an hour and you can just lie there and luxuriate in the warmth and comfort of that space between sleep and wakefulness? That's where I am.

April 18

I think I'm ready now. I just need one moment, one moment of calm and privacy to take this final step. I hear my children's voices, mixed with those of hospice workers or friends. I love them all, but I want them to leave me alone just for a minute, just long enough for me to finish this. I hear Emma and Karen's voices. I know they're here. Emma said something about flowers blooming and birds singing. It sounds like a lovely day to die. I just need to wait for the right moment, a moment when I'm alone.

I can't tell them I want to be alone. The other me, the me before this illness, would have done her best Garbo imitation and cleared the room. Here I am on the day I'm going to die thinking about Greta Garbo.

There's a new voice—Jerry. And his wife, Beth. More voices. Janie. The sons-in-law Aaron and Jason. These children of mine who will not let their mother alone. I want peace. I want perpetual light to shine upon me.

Every voice in the room is familiar. The nurses have gone—it's just me and the kids. There is a silence and I know they're all staring at me. Waiting for me. I hate being put on display. The only thing left in my bag of tricks is dying—I can't do anything else.

After a while, I hear two of my daughters start singing to me. *Summertime*. It's a song I used to sing to them when they grew too old for lullabies. Their voices are soothing.

Really, when I think about it, I don't know any better than they at what moment death will come. If they all were to walk out en masse and leave me alone, would death really come at my command? Perhaps they aren't waiting for me to do anything. Perhaps they're merely waiting with me. We're waiting together. I'm not alone after all.

This isn't so bad.