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“Margaret’s” Children Remember

Interview by Christine Mitchell

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Christine: I never met your Mom. What was she like as a person, before she was sick?

“Paul”: She was the person that would do anything for you. She’d give you the shirt off her back. If she had five bucks in her pocket, she’d give it to you. Even when she first got sick, she didn’t tell us, you know. She would say, “I don’t want to be a burden to you guys.”

“Mary”: She was a nurse. I think it was almost two years that she kept the illness from us.

Christine: How did you figure out that something was wrong?

“Martha”: Actually, she lost her job. I guess she started messing up at the hospital, and they told her, “Maybe you should take some time off work.” And there was a lot going on. I was just graduating from high school. Paul was just graduating from college, and my parents had just been divorced. It was kind of a mess. So they [at work] said, “Maybe you’re stressed out; just take some time off work.” I remember the day that they told her. She was standing in this living room, crying.

Mary: That’s when she started going to the doctor, unbeknownst to us.

Paul: She was 48.

Mary: At that point she could still talk, but all she would say about it was, “I just want to get better so I can go back to work.” She loved being a nurse. It was the right job for her. And I think she really wanted to believe that she would get better and go back. But I also think she knew deep down inside what was going on with her, because she was in the medical field.

Martha: She . . . her handwriting, she’d write stuff and she’d skip words, or her sentences weren’t complete. She was also working two jobs.

Mary: Yeah, our parents had gotten divorced and she was “it”. It almost made sense that she’d be overtired and maybe just not functioning properly. So I didn’t really think . . .

Paul: Then she had a brain biopsy.

Martha: When the result came back, we were all upset. We all had a hard time with it because we had been really convinced that it wasn’t Alzheimer’s disease. It’s scary because they say it’s such an awful disease. And no one seemed to know why she kept getting worse, so fast.

Paul: I’d be on the internet for hours, till three in the morning, trying to figure out different ways to attack it. I had power of attorney at the time. We would bring stuff to the doctors and ask, and challenge them: “What new medicine can we use because the stuff we’re doing is not working?” He was like, “Well, we can try that.”

- Mary:** I was in college when it started getting real bad. But before that, she would never tell us when she had a doctor's appointment. She would walk from here to the Brigham and Women's Hospital [about five miles] just so she wouldn't have to burden us with having to drive her, because there came a point when it was clear to us that she shouldn't drive anymore.
- Martha:** Yeah. I remember one night, [Mary], me, and Mom went out to dinner. It was fall, winter maybe, so it was dark out early. Remember? We went to Old Country Buffet. She really wanted to go to Old Country Buffet. And we're driving down Route 1 and I'm sitting in the front seat, praying because, like you said, her reaction time was just not good. I remember saying "Do you want me to drive, do you want me to drive?" And she was just frustrated with herself, and she was just like, "No," you know, really angry almost. And shortly after that she stopped driving.
- Christine:** When you got power of attorney, was it for financial stuff or for healthcare decisions?
- Paul:** It was everything. I was her healthcare proxy.
- Christine:** When you talked to her about healthcare decisions, did she say anything about what she would want or not want?
- Paul:** One of the things that she did not want was to go into a nursing home. She didn't want to be the old lady in the nursing home.
- Christine:** Was she specific about anything else?
- Mary:** Being a nurse, you know, she's seen people, and she'd say, "That's no life; that's no way to live your life."
- Paul:** Yeah. Like Alzheimer's. I would not want that to be me. Just seeing my mother go through that. That's no way to live.
- Christine:** What was it like?
- Paul:** I almost think that the first day, when she went into McLean [a private psychiatric hospital affiliated with Harvard Medical School], was worse than when she passed away.
- Martha:** Yeah, I think so.
- Mary:** I mean, we had to let go.
- Paul:** We had no more control. We knew she wasn't coming home.
- Mary:** We were all in our twenties, and we had all pretty much put our lives on hold for five years to take care of her.
- Paul:** I bought this house at 24. At that point I didn't really want to buy it. I was two years out of college and like, you know, I was trying to have some fun. But the best thing for her was to make sure that she stays here as long as possible.
- Christine:** So much for going out drinking with the guys.
- Paul:** Yeah, that didn't happen.
- Mary:** There was a point when we were all living here. It was [Paul] and his wife, who was his girlfriend at the time. And I was home from college. I graduated. [Martha] was here with her baby, and my mother.
- Martha:** And we were all living here at the same time. It was such a nightmare.
- Christine:** Did your mother like it? Or was it too much stimulation?
- Martha:** I think she liked having us all around. I don't think we liked it.
- Mary:** Yeah, it was very stressful. I think maybe we didn't realize how far along her disease was. The day that we initially brought her to Brigham & Women's Hospital I was taking care of her during the day while they were at work. I was convinced that she just wasn't feeling well, because her behavior had changed.
- Martha:** She couldn't talk.
- Mary:** Right. She couldn't talk. She could only say the word "two" in a high-pitched, chant-like way. And she would get really loud. That's just how she communicated; like if she wanted something, she'd say "two-two-two-two." Or, if one of us would leave and she didn't want us to go, she'd stand at the door and scream "two" over and over again.

- Christine:** What happened when you brought her to the Brigham & Women's Hospital?
- Martha:** When we went to her appointment, they said, "She has two years left." And we were, like, "What?" We were totally in denial about it. "Two? Come on, she's healthy, you know." But also she was really violent. I think they put her on Ativan, and admitted her.
- Paul:** Yeah, they restrained her.
- Martha:** Because she wouldn't sit still. They had to heavily, heavily medicate her. And she was strapped down to the bed. It was horrible. We thought, "Well, she just wants to go home. So we decided. "Let's just take her home." They medicated her, and we got her in the car and brought her home, and she took a nap. And then —
- Mary:** All hell broke loose.
- Paul:** Yeah, she was pretty violent — punching us. We got her calmed down, because we were used to having to calm her down anyway. Sometimes we'd have to actually lay in bed with her, or just sit there — I guess so she knew someone was there — and then she'd fall asleep. So that's what I did. I sat with her and then she fell asleep again. But when she got up, she started falling down. And then she tried to hit everybody that was in her way, so we finally had to call an ambulance for her. And that's when they put her in McLean Hospital [a psychiatric facility].
- Martha:** Before when she was sick, she was never violent, never. She hardly ever yelled at us.
- Christine:** So when you brought her to McLean, it was unexpected?
- Mary:** Well, yeah. Well no. . . .
- Martha:** They [the ambulance] took her back to the Brigham first.
- Mary:** What happened was the doctors at Brigham kept telling us all kinds of different scenarios and, for some reason, we met this young doctor.
- Martha:** He was an OB/GYN [a specialist in obstetrics and gynecology].
- Paul:** Yeah, he was an OB/GYN intern or something.
- Christine:** In the emergency room?
- Paul:** Yeah.
- Mary:** And he really pushed us to see that something's really wrong here.
- Martha:** His father was a neurologist.
- Paul:** Somehow he got her into McLean.
- Christine:** So when she went to McLean, what did you think?
- Mary:** Well, the day she went in was very emotional for all of us. It was worse than when she passed away, because we knew that she wouldn't come home. And we had all rearranged our lives and put a lot of things on hold. Our lives revolved around her. For the first week I sat on the couch harassing my brother [Paul] at work, saying, "What am I going to do with myself? You know, my days were spent taking care of Mother."
- Martha:** She was more work than a baby. It was just an empty, lost feeling, as if she had died.
- Paul:** They [the staff at McLean Hospital] were really good. We were going every day [to visit], and they said, "You can't come every day." I'm like, "We're coming every day." And they'd say, "You're going to drive yourselves crazy." And I was like, "No, I don't think so." Then, you know, gradually, slowly, we were all right. They said, "For five years, you guys took care of her. Take a little breather here; we can handle it, you know."
- Christine:** Did she recognize you still when you visited?
- Paul:** At the beginning she did. Then, not so much.
- Mary:** But she would definitely look happy when we saw her. You know, her "two" would get higher pitched and faster. I mean, she always seemed excited to see us; but I don't know if it was because she knew us or just because we looked like a friendly face.
- Christine:** Did she ever come home again?
- Paul:** We brought her home for one day. We had a cookout.
- Mary:** It wasn't for her. It was for us really. Like, she had no clue.

- Paul:** We begged the doctors. We said we just want to have her home one more time, just for us. And he was like, "I don't know." I'm like, "What! We cared for her for five years. Nothing's going to happen to her once she's there." And he said, "Well, you know, she's still my responsibility." I went, "Listen, just do this one thing for us." So, she came home, one last time.
- Martha:** One of the workers . . .
- Mary:** . . . came with her. Our favorite one came with her.
- Paul:** So she was home for a little while. And we took her out in the back yard and she did her laps. I mean, she would just walk and walk and walk.
- Martha:** Because we knew that she was getting —
- Paul:** That was it, yeah.
- Mary:** . . . to a point where we would never have her home again.
- Martha:** It was — yeah, it was definitely for us.
- Paul:** Going to visit her was really hard, because she wouldn't sit down. She would roam the halls . . .
- Martha:** . . . all day . . .
- Paul:** . . . unless she was sleeping.
- Mary:** We'd have to follow her around with food to feed her.
- Paul:** She was on, what, 30 combinations of different medications? They would say, "We're going to try this new combination [of meds], what do you think?" And we'd say, "Okay," because we were trying to get her to a point where she could go to a nursing home. Then, a couple days would go by, and they'd say, "No, that didn't work." I'd get another call and [they'd say], "Now we're going to try shock therapy." And that worked for, I think, about a week. Calming her down, I mean. Then, she just went back to walking, pacing really, and yelling.
- Christine:** It was a locked ward?
- Mary:** Yes. That was the thing about our Mom, even when she was pacing, even when she couldn't talk or express herself, you could feel how loving and caring she was. She'd give you hugs and kisses. They all got very attached to her, the nurses, the social workers, the doctors. They've said to us that she's their favorite patient.
- Martha:** Like her nurse was probably around the same age as us. And she had a mother; her mother was about the same age as our Mom. So she had a real hard time with what happened to my Mom.
- Christine:** You mean about medicating her with morphine?
- Martha:** Yeah, a real hard time.
- Mary:** She actually refused to.
- Martha:** There was a very emotional meeting. We said, "You have to understand — if she doesn't want to live like this, we don't want her to live like this. And to have her carry on the way that she is, it's not fair to her, or to us."
- Paul:** Towards the end, before she went into the hospice, we talked about morphine and all these other drugs. We had to meet with Dr. Brendel [the chair of the ethics committee at McLean Hospital] and we had to write a statement [see "A Letter from the Children"].
- Martha:** And we had to go in and have meetings about ethics.
- Paul:** We can give you all that stuff. I have it all on the computer. I can e-mail it to you.
- Christine:** Thank you; that would be great. What did you write in your statement?
- Mary:** It was about what we wanted for her.
- Paul:** I'd have to re-read it, but yeah, we talked about our mom, what type of person she was. We wanted them to understand why we were making the decision [about giving morphine] that we were making, because she wouldn't want to be living this way, and it was no type of life and no quality of life for her to have, to just be walking around aimlessly. I mean, she started to get really sick at the end, and I felt like she was suffering. She was just always riled up. Her chanting and her walking and her pacing, and she was never calm. Maybe she was trying to tell us, "I just want to be peaceful," because she wasn't.

Martha: Yeah, she was never at peace.

Christine: What did you want your mother's caregivers to do?

Paul: I would probably say to the medical profession and people in the nursing field: do everything you can to save someone; but in a case like this, the thing to do is to just let them go. Sometimes, you people shouldn't . . . everything *shouldn't* be done. *Don't* pull out all the stops, because it isn't necessarily the best thing for everyone. At the end we said, "Listen to what we're saying. We're her voice, okay. We're telling you what's best for her."

Christine: What happened when you had the ethics meetings?

Paul: I mean, we sat down with, like, the state. We sat down with everyone.

Mary: Everybody under the sun — from the Alzheimer's Association, Dr. Brendel, Dr. Brendel's colleagues. I mean. . . .

Martha: It was funny because everybody that we met had the same reaction. The first thing that they would say is, "Oh my God, you're so young." Like every time. So many people said to us, "We're so amazed with what you've done for your mother." For us, we were young, our mother needed us, we didn't know anything different. We needed to take care of her. We just put our lives on hold.

Paul: It makes you mature really fast. You give up a lot of stuff. I would do it all over again in a heartbeat, you know, to make sure that she got everything right. But it really makes you put everything in perspective. You know, money, houses, cars, all that stuff. I have a totally different outlook than if I — if this didn't happen to me.

Christine: So you had meetings with the ethics committee?

Mary: Yeah, and that's when we had to write that letter to explain ourselves to everyone. I can understand their side of it. But . . .

Christine: What was their side?

Paul: I think a lot of them worried, "What if this is a Terri Schiavo case?" You know, what if the news [people] got wind of something like this? When we met with them, they all felt for us. A lot of them got to know us really well, because we pretty much poured our life out to them. We told them everything about us; what we've done and what we haven't done. What's worked; what hasn't worked for our mother. A couple of people said, "What you guys are doing is the right thing." Not for every case do I think it's the right thing. But for someone who was as loving and caring as our mother, and then to see her in this state — we talked a lot about dignity.

Mary: When it came to the end, before the idea of hospice came up, [the staff at] McLean started to say "Okay, well, we'll consider end-of-life care." But they're a mental health facility; they're not a medical facility. So they weren't equipped to deal with her. So that's a lot of the reason behind all those ethical meetings.

Christine: Were they upset about giving your mother a lot of morphine?

Paul: Some of them were.

Mary: Yeah, some of them definitely were. But she wouldn't eat, and she was always upset and restless.

Martha: She was never a tiny woman, but when she first went into the hospital she was like a size 14. And when she died, we actually had to go buy her an outfit because she had lost so much weight, and we bought her a size six.

Mary: Me and my sister said, "She'd be so pissed that she couldn't enjoy this!"

Christine: Did you feel upset with the nurses that wouldn't agree to give her morphine?

Martha: We were aggravated.

Paul: Yeah. I was angry, to be honest with you. You know, I was like, "Who the hell are you to tell me what my mother wanted . . ." you know, "and what we want for her, and what she wants for herself?" You know, it's almost like we have no right.

Christine: What did they say?

- Martha:** Her main nurse, the one that was the same age as us — later, she told us that her mother had cancer or something like that. So it was very personal for her, that she didn't want to be involved in using the morphine to let our mother die.
- Christine:** Did you all talk to each other about euthanasia?
- Paul:** Yeah. I mean, is that what we did? I don't know. I don't think it is, but . . .
- Mary:** It was more of an afterthought. I think at the time we just did what we thought was right. And then, you know, people started saying stuff to us like, "How could you have done that?" I mean, it was just a few people, but it was after the fact. And we were like, "Well, what did we do?"
- Christine:** People in your family? Or people who were taking care of her?
- Martha:** Probably a little bit of both.
- Paul:** The other thing is, it was just us. My mother has brothers who are alive and well, and her mother. And they just completely washed their hands of the situation. Right before she went into hospice, we did the Memory Walk. And we were trying to get our family involved in that. And they were kind of like, "Well, what's going on?" I remember [Martha] talked to our aunt and uncle about moving her to a hospice. And they said, "Hospice, what are you talking about?" And then my aunt had to leave the room because they couldn't be actively involved. So it was just us.
- Martha:** We invited them to the meetings that we had at McLean and everything; but there were always these excuses, like, you know, "I can't leave work today."
- Christine:** Did they just not realize that she was suffering or dying?
- Mary:** I think they chose not to.
- Christine:** Did they think you did something you shouldn't have done?
- Paul:** I think one of our uncles had that impression until everything came out [at the funeral], and we gave a eulogy at the Mass for her. He came up to me after and said it was beautiful. I don't think he really understood the extent of what was going on with her.
- Christine:** What happened when she went to hospice? I know there was some discussion before she went, asking them in advance if they were willing to do terminal sedation.
- Paul:** Well, [our mother] was still very active. I mean, she was strapped into a chair, and she was very loud and . . .
- Christine:** At McLean?
- Paul:** Yeah, at McLean. And even the first day she went into hospice, I remember the nurse practitioner came in and he said he wouldn't have taken her if he had realized how bad she was. And I got right on the phone and called [the social worker at McLean], because we were like, "Oh my God, what's going to happen to her?"
- Mary:** Yeah, "Are they going to back out of this?"
- Christine:** What happened?
- Mary:** When he came to see her [at McLean], she had been medicated and she was quiet. And then she walked into the hospice screaming. And we thought, "oh no!" you know?
- Paul:** Then one night they called us [from the hospice] and we all rushed over. We didn't think she was going to make it. They said, "We're going to bring her to McLean. You guys can go home." And I'm like, "I'm not going home." We had the priest come, our family priest, and he gave her the Last Rites. And even as we were praying with her, we kept checking, "Is she still breathing?" Like, you know, because she would breathe, and then she wouldn't. And then she would breathe, and then she wouldn't. It was scary to watch. Then reality set in: "She's not well, you know. Look how she's breathing." And we had another nine days after that, right? She'd be breathing and then she'd stop for like 30 seconds, you know, and then she'd start breathing again. So I'd stay there [in her hospice room]. . . .
- Martha:** Yeah, he wouldn't. . . .
- Mary:** . . . he wouldn't leave.

Christine: Sons and mothers.

Mary: They have a little booklet [at the hospice] about what to expect when someone is dying. And they kept telling us to tell her that it's okay for her to go, that we will be okay without her, and that we love her. So we were talking to her. And we thought, "She's not going to die."

Martha: And then there were little things like, I swear to God, she said "[Mary]" a couple days before she died. Her eyes were closed, but she was reaching out. And then she just sat up, and I swear to God she said "[Mary]," and then laid back down.

Christine: What's so hard is not knowing when it's really the last breath. I don't know what happened to your mother, but a lot of times when a person is dying they will take a breath, and then it'll be minutes, minutes, and you've just convinced yourself that they've died, and then they go "Aaah," and start breathing again.

Paul: Yes, exactly, that's the way it was.

Mary: She'd start breathing again.

Martha: They told us that she would die with who she wanted there, and [Mary] and I weren't there. I don't know if I would've been able to handle it.

Mary: I don't think I would've . . .

Martha: He [Paul] was there. And her favorite aunt and husband — they had stopped by after church.

Christine: What happened?

Martha: I just know he [Paul] called us and said, "You better come now." And when we got there, he was standing at the doorway. And I knew. I knew when I was going there. Because when I was getting dressed in my room, I started coughing real hard. I just had this feeling. I looked at the clock, and when I got there, it was the same time. I asked [Paul] what time she died, and it was the same time that I started coughing really hard in my room. It was . . . she was gone.

Mary: She died on a Sunday. I mean, my mother was very religious. We're Catholic. And they say people that die on a Sunday go straight to heaven. So we're like, "Oh, it's a good thing she got in on a Sunday." I don't know if it's true or not, but I believe she went straight to heaven.

Christine: So after you had the funeral, did people in your family stop saying things about the medication at the end of her life?

Paul: Actually, it more intensified.

Mary: Yeah, it got worse: "How can you do that, put her in the hospital like that and put her in a nursing home and let her die?"

Paul: People are very critical when they're not in the position to really understand. It was upsetting to hear people saying things. Then you question what you've done; like, "Did we do the right thing? I mean, did we care for her the right way?" Then we would get angry, like, "How dare they make us question our decisions, things that we knew that our mother wanted?" But you second-guess yourself, you know, when all these people are saying things. But my mother had stated what she wanted, you know. And if we didn't follow her wishes, then we would've been doing her an injustice.

Christine: Do you think it was the medication that killed her?

Paul: I don't. . . .

Mary: She [her disease] was so far along, and we didn't even know it. To us, it was really fast for us. Five years sounds like a long time, but it's not really. We had five years; bang, it's over, she was gone.

Martha: They had told us she would forget to swallow and forget to breathe. And that's what was happening at McLean Hospital. So. . . .

Paul: I don't think that the medication killed her. I think that if she had to be intubated and then put on a machine, there might've been a possibility that she would've lived a month, maybe longer. But she was so far along.

Martha: We had an autopsy and donated her brain. They said it was severely atrophied, and there was something about the brainstem, I think, as well.

Christine: Do you have pictures of her?

Martha: That's all her [pointing to a glass-covered collage of photos on the coffee table]. This is her, the Mom we remember. . . . That's her, you know, just being goofy. And that's her . . . she loved animals. That was our family dog. That's her wedding picture. She was very beautiful. That's when she was sick. This is the day that she realized that she wouldn't go back to work, and they had a little party for her. That's her in the middle. They gave her a plaque, you know: "Great friend and Great worker." It was a really emotional day. And that's her nursing school graduation. This is the time we brought her home from the hospital, just for the day. She's young, here. . . .

Note: Throughout this case, the names of the patient and her children have been changed. Quotation marks have been used around these changed names at their first appearance in an article. No other information has been masked or changed in this case. The information presented in this case is used with the permission of the patient's children and the other parties involved.