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## Family Portrait

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## Personal Narratives

### Family Portrait

Joseph J. Fins

When I last saw my dad he was propped up on a gurney smiling at us. He turned to us and simply said, “What a beautiful family portrait.” We smiled back, told him we loved him and that we’d see him soon. Then he was off to the ambulance that would take him to Manhattan to repair the 9 centimeter abdominal aortic aneurysm that was discovered earlier that morning.

No big deal, right? It was going to be an endovascular repair and he was stable. He was coming to the academic medical center where I work and they do this sort of thing all the time. Yes, he was 93 but otherwise in great health. His mind was keen and his memory sharp. The vascular surgeon, who was a colleague, and a father of my son’s classmate, would slip the plastic inner-tube into the aorta, like fixing a flat tire. And we’d take it from there. No big deal.

As the ambulance sped to the city, my brother-in-law drove cautiously navigating the January snow. As he did, that comment about a family portrait came back to haunt me. Why did he say that? More wise than sentimental, my father knew what he wanted to carry forward with him and the final paternal lesson he would convey. My sister and I were together, embracing and supporting each other. We were accompanied by her husband and my fourteen year old son. The message was: Stay together; we are a small family. What was left unsaid was that, “Soon, I will be gone and you will have to rely on each other. This family portrait is the image I will carry forward, as he carried ours.

As we crossed the Tri-Borough Bridge coming into Manhattan all that was in my mind’s eye when my wife called from the Emergency Room at my hospital.

“Joe . . .” I detected a weakness in her voice.

“Not good?”

“No, the ER doc wants to talk with you.”

Her words evade me but she told me that several blocks from the hospital my dad had a cardiac arrest in the ambulance and that they were coding him in the ER. What did I want to do?

I braced myself for what I would say and how I would process this, immediately shifting roles from grieving son to studied physician—no check that—bioethicist. For a moment I asked myself, *wasn’t he meant to be DNR during his ride into the City?* He had a portable DNR order—or at least that was the plan. From an academic, and better yet, legal point of view, he was not meant to be resuscitated. Those had been his preferences.

But then I thought better of it. That was a scholastic distraction that wouldn’t make a difference now: they were already doing the Code. And there was no time to bring that up. That question would be best left for later. No, they needed an immediate answer.

“Stop.”

“Ok.” She hung up.

I turned to the back seat and told my sister that dad had died. She started to wail the sort of cry that one experiences on those occasions when you lose a parent, spouse or child, when a part of you yourself dies. Yet amidst that tragedy was a moment of immense pride. My little boy reached over and gave my little sister the biggest bear hug of his life. In a reversal of roles, she and I had moved up a generation in that sequence of passages and my teenager became the consoler in chief. A tectonic generational shift. As my dad’s son, I was deeply sad—and as a father, I was consoled by my son’s gesture.

Still, I sat stunned, staring at the curve coming off the bridge down to the FDR Drive. Somehow I found myself absorbed by the black and yellow arrow markings on the concrete border guards that whirled by. In a hypnotic gaze, I started to think about life without Dad.

That is, for a minute, until the ER doc called back. “When I went back in, they had got a pulse.” Now the question that tested me as a son and a bioethicist: “What do you want to do?”

Remarkably he had come back. No one did that. In all the years that I ran codes as a medical resident only a handful of patients ever rebounded.

This didn't happen in real life. And, my dad was a nonagenarian.

The ER doc wanted me to talk to the vascular surgeon. In a rush, he got on the phone. He told me he could still do the surgery but we had to decide right away. There was no time for discussion, just a decision.

I had prepared for this decision my whole life. And my father prepared me his whole life by instilling values and hopefully good judgment. Earlier in the day he had been reluctant to have the surgery. He just wanted to go back to the senior residence and wait it out, whatever that would entail.

In response, we had implored him to have the surgery since dying of a ruptured aneurysm at home didn't seem like a particularly humane exit. He might experience pain and it could happen when he was alone. Besides, only yesterday, he had a normal day. He walked to breakfast, lunch and dinner unassisted, and watched the news and talked politics with anyone who would listen. He had been at the top of his game, save for the glaucoma that kept him from his beloved *New York Times*.

We urged him to have the aneurysm repaired but he demurred. So we nudged him with some guilt, "What would Mom say?" Our mother had died nearly twenty years ago and he was still very much in love. He looked me straight in the eye and said, "She'd say, 'What took you so long?'"

So much for guilt.

Ultimately, he relented seeing there was an upside to the repair. If it went well, he'd go back to his life. If not, nature would take its course. Either outcome was fine with him. And then there was his altruism. Consistent with a life narrative of self-sacrifice for his kids, he agreed to surgery to protect us from loss and sadness.

Now, as we raced to the hospital, we were asked what was best for him. The decision was out of his hands and with us—his surrogates. The odds did not seem good but the surgeon was convinced he could still do the surgery, *if* we acted immediately. My intellectual impulse was to let him go. After all, he really didn't want the surgery, had a DNR order, and was in a precarious state.

Years ago when he had had a TIA, we spoke about high risk, high reward treatment decisions in the context of a recurrence. He would take the risk if it could return him to his former self. He didn't fear death but dreaded permanent impairment, which would rob him of his mind and his independence.

This wasn't exactly analogous, but the surgeon indicated a good outcome remained possible. Besides, *my* heart was pulling for *his* aorta. It wasn't even a close call. We agreed to the surgery and to suspend the DNR order during the peri-operative period.

My dad was rushed to the OR and we found a deserted waiting room for our vigil. Usually swarming with outpatient surgeries it was deserted on that dark winter night. We had to turn on the lights.

It was surreal. Time passed and passed. An hour went by, which seemed like a good thing. He hadn't died again. The doctors were still in there: the longer nothing catastrophic happened, the better. We grew a bit more confident, so much so that my brother-in-law and son went out to get pizza. We hadn't eaten for ten hours yet ate without an appetite. Was this to be a last supper?

Three and a half hours later, the surgeon emerged. A fit man in his 40's, he looked drained and exhausted. He seemed to have good news. They got through the surgery. But I felt something was wrong. He didn't have that exhausted yet triumphant look of the battle tested surgeon. He seemed defeated, "... And when we were done, he had another cardiac arrest. They are coding him now."

Same surgeon, same laconic question, "What do you want to do?" But now it was different. We had tried. He had tried and we had failed to save his life. We told him to stop.

The room grew still but there were no tears. Instead we had a sense of *deja vu*. Hadn't we done this before? How many times can your dad die in one night? Like Joan Didion's *The Year of Magical Thinking*, a memoir of mourning following her husband's death, sorrow induced my own magical thinking. I wondered, would my dad rebound again? Maybe we should hold off on letting people know. Might he do it again?

Gracious even under pressure, the surgeon politely thanked us before rushing back in to let my father die in peace. But then, nothing happened. Another hour passed.

Again, he emerged only to tell us that when he returned to the OR my dad had been resuscitated. And he was still alive. But again the surgeon's look betrayed an ominous challenge. During the surgery, an aortic balloon pump had been placed to stem the bleeding and assist his heart. With the aid of a diagram sketched on the discarded pizza box he explained how the balloon would need to be deflated to complete the surgery and how this could lead to cardiovascular collapse. It could be perilous.

Heartened by possibility, I asked if we could wait and let him stabilize before deflating the balloon, and our hopes. The surgeon said yes, but it would still be risky. For one who has written his fair share of articles on medical futility, I sought to focus on possible remedies. It was an exercise in technical reason obscuring value choices and clear thinking, just what the ethnographer Robert Zussman described in his book, *Intensive Care*. I had taught that book for years and now was falling prey to what I had hoped to prevent in trainees. Like the novice who resorts to physiological language when confronting a patient's death, I had sought refuge in the hemodynamics of aortic flow to obscure hard choices. It was an evasion, a false channel of hope.

That is until, my sister asked, "Joe, what are you saying? Hasn't Dad been through enough?" And of course, she was right. Hope had hijacked my rational self. Where was the doctor to whom the family had always looked for steady and sober advice? At that moment, I was more a loving son than an analytical physician, buoyed by my dad's resilience, but stricken by impending loss.

There are many lessons from this long January night, but I will share only two. First, even physicians trained in the art have families and feelings. Physicianly comportment only takes you so far. Second, when we approach the grief of other families we should remember our own. Their demands for "futile" care, which can be perceived as delusional and irrational are the result of the same forces that

led me to hope against hope. And I should have known better.

If after thousands of ethics consults, I could fall prey to the power of filial love, we should be more tolerant of families as they confront their own tragedies. It is never as simple as the philosophers would have us believe.

Ultimately, what we thought did not matter. As we spoke to the surgeon he got a call from the OR to tell him that my dad had died for the last time. He told us the news with kindness and proper solemnity. I thanked him for his heroic efforts and shook his hand.

It had been a long night full of life lessons for this humbled bioethicist, and still bereaved son.



## Found in the Translation

Kathleen N. Fenton

"They told us she was cured, and then all of a sudden they told us there was nothing more they could do," Dad repeatedly told me in the first months after we lost my mother to stomach cancer. That, of course, was not quite true: in fact, there had been no evidence of tumor recurrence, until there was.

I am a cardiothoracic surgeon, the oldest of three "kids" in the family. My youngest brother is a Catholic priest. Both of us deal with life and death every day, and for years we had been trying to get our parents to formalize advanced directives. Finally, once my mother was in hospice, we got them done, with Mom and Dad both, who at that time were in their early 80s. They had been married for 57 years and Mom was dying of recurrent gastric adenocarcinoma.

Throughout the course of Mom's illness, I had the advantage of understanding, of reading between the lines, of putting together the pieces of the puzzle. I was at a medical conference in Seattle when we first realized she was sick. The night before