

Nothing by Mouth

I have a well-worn card in my wallet. On one side, there is a bulleted list. The first item says, “I have no pancreas.”

This is the story of how I came to be without a pancreas, but it’s also a lesson about why I need a card to prove it. Unlike my medical alert bracelet for use in case I am incapacitated, this card is for when I am coherent but an emergency room physician doesn’t believe I can give an accurate accounting of my own internal organs.

My medical drama began in 2010, when I began having severe upper abdominal pain with nausea and vomiting that made me a frequent flier at my local emergency room. When the blood tests came back normal every time, I was accused of drug seeking behavior, and any attempts to treat my now alleged pain were stopped. Although it was undeniable I was seeking painkillers, the reason was in dispute. Once I was labeled as an addict, I was never examined by emergency room physicians, who now just lectured me from the other side of the room; nor was I given any recommendations on how to deal with my supposed addiction.

On several occasions, the staff at the entrance to the ER tried to help me back inside because they couldn’t believe I was leaving in such obvious pain. They didn’t think anyone could fake looking so miserable, but the doctors had seen too many addicts to get past their bias. I understood in some ways, but it bothered me that patients who were addicted to narcotics were being judged rather than treated. The behaviors of those patients with drug addictions were making it harder for me to get an appropriate diagnosis, but those patients deserved treatment, not judgment, as much as I did.

Fortunately, my gastroenterologist and my primary care doctor believed I was in real pain and kept seeking the cause. I was referred to Dr. Smith, a general surgeon, after more than a year of pain. It was discovered I had a cyst on my liver and the hope was its removal might relieve my pain despite being told that liver cysts were a common benign finding.

I felt comfortable with Dr. Smith immediately. Maybe it was because I could look him in the eye as he was close to my height of five-feet-five-inches. Or maybe it was because he was bald and the ring tone on his cell phone was “Bad to the Bone.” His white lab coat was pristine and, suffering waves of nausea, I feared I might vomit on it. He sent me to radiology to get an abdominal CT scan. My abdomen was hurting so badly that when the little cartoon face on the scanner pursed its lips and the machine said, “Hold your breath” I felt the tears running down my face.

Dr. Smith was blunt—like someone who doesn’t have time to mince words in an operating room. The results of the scan were obvious -- so textbook that he excitedly gathered some medical students to look at it. “You have pancreatitis and can’t go anywhere. You need to stay right here and be admitted to the hospital. You could die.”

“OK,” I said, overcome with relief that my pain had a name and was no longer in question. Still I was scared and upset I had suffered for so long with a life-threatening illness because assumptions about drug seeking behavior had gotten in the way. The emergency room physicians were not the only ones who had missed the diagnosis. I had been referred to two pain clinics. When the first one never returned my call, my doctor sent them a letter reassuring them I was not drug seeking. They still declined to see me. The second clinic sent me to see a nurse practitioner on their staff who tried several medications typically used to treat fibromyalgia or depression. When those not only didn’t help the pain, but made it worse because they stimulated

my appetite, she told me, “You’re not really in pain. You just like the way the pills make you feel.” To realize now I had acute pancreatitis at that moment, a potentially fatal illness, makes me livid. I was so distraught that day I didn’t feel comfortable driving my car and I walked the five miles home while sobbing and vomiting along the way.

I learned from my doctor that the pancreas is a finicky fish-shaped organ that releases proteins called enzymes to digest food, and contains insulin producing cells called islets that control blood sugar. Pancreatitis is an inflammation of the pancreas for which there is no medication. As one doctor put it, “Starvation is the only real treatment.” A sign went up on my hospital room door saying “NPO” which stands for the Latin phrase “nil per os” or “nothing by mouth.” That means not even water was allowed past my cracked and parched lips.

It was determined that my pain came from a birth defect called pancreas divisum. Pancreas divisum affects two-percent of the population, but only a fraction of those people ever have symptoms. The pancreas starts as a divided organ in a developing fetus, but eventually forms one organ before birth. My pancreas had not completely “united” and so whenever the pancreatic enzymes were triggered to digest food, they were unable to flow out of my pancreas properly. This caused the pancreas to swell whenever I ate, leading to malnutrition. I had broken four bones in the previous three years due to my body’s inability to obtain the proper nutrients from the food I was able to keep down.

Some five-hundred thousand people have chronic pancreatitis in the United States. Alcohol causes a significant percentage of the cases of pancreatitis (although the percentages in the literature vary to between twenty-five and seventy-five percent), but often the cause is unknown or “idiopathic.” I spent the next ten days in the hospital before I was well enough to go home, but I only got a short reprieve before the pain returned. Every time I went to the hospital

with pancreatitis symptoms I was asked, “How much did you drink?” It was almost if the nurses and doctors wanted it to be alcohol-related. Maybe then they could say, “*This horrible pain will never happen to me.*”

I had two surgeries to attempt to alleviate the pain. The first surgery, in March of 2012, was performed nearly two years after I first consulted with Dr. Smith. During that time, I was in and out of the hospital every few months for a bout of pancreatitis, and so surgery became the best option for treatment. Dr. Smith performed a transdoudonal pancreatic sphincterotomy. This is a fancy way of saying that he tried to surgically open the places in my abnormal anatomy that were causing the pancreatic enzymes to stay in my pancreas and digest it, rather than the food I was eating. Having an organ digesting itself is as unnerving and painful as it sounds.

This procedure was a conservative first step in trying to alleviate my pain. Nine months later, after nearly three years of pancreatitis every few weeks, it became clear that a more drastic surgery was needed. On December 12, 2012, I had my pancreas removed. I was not superstitious, but I was hoping that the number twelve was a lucky one for me. The islet cells were extracted from my pancreas nearly two hours away at a hospital lab. Then those islet cells, crucial to keeping me from becoming a diabetic, were carefully transported back to me, where they were injected into my liver through the portal vein. The entire procedure is called a total pancreatectomy with islet auto transplantation. The “auto” part refers to the fact that my own islet cells are used, and so rejection is not an issue -- a big bonus because that meant I didn’t need to take the anti-rejection medication that can leave a patient susceptible to infections.

I have lots of memories of the twelve days I spent in the hospital after the transplant -- both good and bad. My first inkling I was going to be all right was when Dr. Smith said that I looked like the “Michelin Man” because of all the swelling. I figured no one would say that to a

person who was dying. The scariest moment was when I was still in the intensive care unit, and I overheard a conversation between the many doctors in charge of my care. The conversation came in brief snippets as I drifted in and out because of the painkillers.

“I think we should do a blood transfusion now.”

My heart raced and I remember wanting to scream from bed, “Yes, just give me the blood!” It was a strange feeling being too weak to yell. Didn’t they know I could hear them talking about me?

“That number can’t be right. We should recheck it. It couldn’t have dropped that much overnight.”

“What number? Yes, it could!” I thought. *You want to take more blood out of me to see if I need a blood transfusion? Don’t you know how crazy that sounds from here?*

“I think we should do the transfusion and not wait.”

I liked this one, this voice without a body that was advocating for me. He’s the one I wanted to make this decision. I fell asleep again, fitfully, worrying if more blood was coming my way. When I woke up later, I saw one of the bags hanging from my IV pole contained a red fluid. I breathed a sigh of relief.

On the twelfth day after my surgery, on Christmas Eve, I was well enough to go home with my new accessory: a feeding tube. My stomach was damaged from the swelling of the adjacent pancreas, and I needed several months before my digestion returned to the point where I could eat solid food. I tried to concentrate when the nurses showed me how to do my tube feeding, but as soon as I got home I had forgotten everything. My first attempt at tube feeding found me pumping yellow liquid all over the kitchen rug while sobbing.

I spent three months at home recovering, which involved sleeping a lot and weaning off the narcotics for pain. The feeding tube was removed after two months, but my first attempts at eating solid food resulted in vomiting. I slowly figured out what I could eat, and how much, since my stomach was much smaller now. In hindsight, I returned to work too soon. I had to sit and rest after walking up a flight of stairs between my office and the cafeteria. I once vomited in the middle of a conference call. By May, I was feeling well enough to fly to South Carolina for my daughter's graduation from college. I ate steak for the first time in several years.

A common complication after the transplant is slow emptying of the stomach, and five years out, this is still a persistent problem. I also developed scar tissue that was removed twice by the same surgeon who did my transplant. Although I was off all painkillers several times in the past five years, some pain has returned due to nerve damage. It is not unlike the phantom pain experienced by patients who lose a limb. In my case, I experience pancreatitis-like pain that sometimes becomes more severe, like an acute case of pancreatitis. This complication is more common in patients like me, who were older when they were diagnosed, and had chronic pancreatitis for many years. I am still relieved to be rid of my pancreas, because pancreatic cancer is more common in patients with chronic pancreatitis, and I don't have to worry about the other complications associated with an inflamed pancreas.

The biggest challenge post-surgery has been the lack of knowledge about islet cell transplants by health care professionals. Whenever I have an episode of severe pain that takes me to a hospital, I must pull out my card to prove I don't have a pancreas. This often has no impact. Recently, I was at the emergency room because of an episode of severe pain and vomiting and a surgeon was paged to my bedside. Despite showing the card to the nurse and the emergency

room physician, the surgeon began by stating he was there to see if he needed to do surgery on my pancreas.

“I don’t have a pancreas. It was removed.”

“Well that is not possible. You can’t live without a pancreas.”

“I had an islet cell transplant.”

I reached for the card again and after a dismissive glance at it he said, “You didn’t have your pancreas removed at that hospital. They don’t do that there.”

“We’re done here,” I said, thinking I wouldn’t trust this doctor to clip my cat’s claws.

During another hospitalization, thinking that the nurses were clear on what organs I had after four days as an inpatient, I overheard my nurse briefing the incoming nurse at a shift change.

“Ms. Phillips, age fifty-four, had part of her pancreas removed, she’s on a ...”

“Hold on,” I interrupted, “I don’t have any part of my pancreas.”

“Yes, well, I know you said that, but it says in your chart that you had part of it removed. They never take out the whole thing.”

“Yes, they do,” I wearily replied. Once again I shared my story about my islet cell transplant, wondering why they would think someone would not know what organs they have.

My card is getting tattered. I think I should get it laminated.