

Two Timelines

Category: Stories

written by Debi Santini | November 14, 2014

Timeline One

Day 1: For over thirty-five years my strong, spirited spouse, Carlo, served around the world in the Air Force. Now retired from the military, he still serves at the air base as a civilian security police officer.

His neck hurts. A lot. He blames the pain on the unbalanced weight of the bulletproof vest that Uncle Sam added last year to the uniform he proudly wears every day.

Even though Carlo is a military veteran, he does not use the VA program for health care.

On this day, Carlo calls his longtime doctor because the pain is preventing him from working, and his hands have started to shake.

The receptionist says that Doc has no openings for eight weeks. Instead, she schedules Carlo to see a physician's assistant in three weeks.

Day 21: The PA orders x-rays and ibuprofen and tells Carlo to return in four weeks. Doc has an opening in five weeks, so we schedule that instead. X-rays at the hospital, then on to the pharmacy. Carlo takes the first giant pill in the car, hoping for relief.

Day 30: Carlo has called several times to ask for x-ray results. Today someone finally calls back to say that the films show arthritis, and that they're sending him for physical therapy.

Day 56: We are checked in at Doc's office and anxious to see him. Carlo's pain is now so severe that he can only stay upright for maybe thirty seconds at a time. He lies on the waiting-room floor for forty-five minutes, praying for his name to be called.

Doc reads the radiology report for the first time: *There is a distinct step-off at C2 and C3 of unknown etiology. Further imaging is recommended.*

Translation: the top two vertebra in Carlo's neck aren't lined up properly, for reasons unknown.

We are confused. No mention of arthritis? What could this mean? No answers.

"The report recommended further imaging, so let's do that," I say.

"We haven't tried conservative measures long enough," Doc says. "Increase the drugs. Continue PT. Come back in two weeks."

"No one ever returned my calls asking about PT," Carlo says.

Doc checks the record: PT was noted, but never ordered.

Day 69: It's the New Year, and we're back to see Doc. Carlo feels lucky to have squeezed two PT sessions into the center's holiday schedule. Still, the pain in his neck is worse, encompassing his whole head now.

Doc says that PT takes time to help, so stick with it and return in two weeks.

Armed with advice from our brother-in-law (a radiologist who lives 350 miles away), our sisters (both critical-care nurses) and physicians from the medical school that employs me, we've decided to stand our ground this time.

"I have a really, REALLY bad feeling about all of this," I tell Doc. We refuse to leave until he orders an MRI scan. Doc isn't happy, but he eventually complies.

Day 73: The scan takes place on a cold Friday afternoon. As the images appear, everyone jumps to attention. When it's over, the radiologist enters and tells us that Carlo's C3 vertebra has been completely shattered by a five-centimeter mass that is displacing the spinal cord and invading C2. He has spoken to Doc, who agrees that Carlo must be admitted to the hospital to stabilize his cervical spine and have more scans.

Radiology transports him to the ER, where a dismissive physician conducts a cursory neurological exam in the hall, then leaves Carlo there for six hours. No scans, consults, admission orders or pain relief.

Finally, a nurse tells us, "Since it's the weekend, you'll be better off at home." They hand Carlo a paper directing him to see a neurosurgeon, give him a strip of white foam to Velcro around his neck and tell him not to stumble or bump his head.

Stunned, confused and terrified, we cautiously drive home. I give Carlo an extra pill to try to get some control of the pain. Then we sob.

Day 78: The neurosurgeon orders a CT-guided needle biopsy and promises to call with the results in three or four days.

Day 92: We called after five days, but they had no results yet. Now, fourteen agonizing days after the biopsy, a nurse calls and tells us that Carlo has a type of cancer known as sarcoma—but there's good news: it is not metastatic, so it hasn't spread from somewhere else in his body.

She says the neurosurgeon doesn't believe the tumor is operable, but wants Carlo to get another opinion. So they've scheduled an appointment for him with another surgeon in three weeks.

Three weeks???

I call the second surgeon's office and tearfully plead. They move the appointment up to the next week.

Day 93: I pick up a copy of the final, official biopsy report.

High Grade Metastatic Sarcomatoid Carcinoma.

It's *not* sarcoma. It *is* metastatic. We scour the internet, but Dr. Google is virtually speechless. Dr. Neurosurgeon doesn't return our frantic calls.

Day 101: The second surgeon sadly shakes his head and sends Carlo home.

For twenty-eight days, all of the doctors involved in Carlo's case have known of the tumor. The biopsy report says that there is more cancer, but no one has looked for it. I've failed to get anyone to return our calls.

"What did I ever do that they won't help me or even call us back?" Carlo asks.

This crushes my heart. So I break the rules and email the doctors, begging for someone to take charge. Doc responds, promising to get tests ordered.

Day 113: Several days of scans have brought us to an oncologist. His verdict: the cancer is in too many places, and it's not clear where it might have started. He recommends radiation and chemotherapy to try to slow the cancer down and buy Carlo more time. Overall, the outlook is very grim.

Day 127: Second opinion: very weird cancer, very rare and aggressive. Carlo has maybe a few months. Exactly what the first oncologist said—but we're shocked, because it took just two weeks to get this opinion, at a major cancer center 100 miles away, when it took almost four months to find out anything from our own doctors.

Day 128: Carlo has accumulated six months of paid time off, during which he can keep his health insurance. To authorize this, the air base requires that he submit a form signed by a doctor. I deliver the form and a preaddressed, stamped envelope to the oncologist's office. They promise to get it signed and sent right away.

Day 155: Radiation was a breeze, but the toxic chemo drugs have brutalized Carlo. Barely able to stand today, he prays that the treatments provide a miracle.

Day 165: Peculiar neurological changes prompt a scan of Carlo's head and neck. The radiologist who initially found Carlo's tumor comes to tell me that Carlo's neck is unchanged, but that there is a large tumor in his brain. They have no way of knowing if it's new, because Carlo's head was never scanned.

Doc emails me that he forgot to order a scan of Carlo's head when the original scans were done. We're stunned that no other doctor along the way even noticed.

Day 169: The oncologist tells us that the brain tumor may be where Carlo's rare cancer started. And that the drugs used in his chemotherapy were not a type that crosses the brain's protective barrier. Essentially, Carlo suffered terribly from treatments that probably couldn't have helped him.

Day 173: A termination notice arrives from the air base human resources department.

WHAT?

They have no choice, they say; it's simply policy. Carlo has failed to return to work, and the signed form that would have excused him was never submitted.

I frantically call the oncologist's office. Three days later they find the form, still unsigned, sitting on someone's desk.

Day 206: The rare, weird, aggressive cancer takes Carlo's life.

He was fifty-eight. He had honorably served his country for more than half his life. Failed by clinicians and staff in our healthcare system—some of the very people he'd dedicated his life to protecting.

Day 271: I meet with Carlo's doctors. Their awkward apologies provide zero comfort. They swear they didn't know that we couldn't get appointments, or that we were repeatedly given inaccurate information. And no one ever told them that we'd called, so how could they have known to call us back? They soothe themselves by saying that nothing really would have changed the outcome.

I tell them that Carlo's life was worth their effort. That, at a minimum, they might have eased his terror.

I suggest that it might help to implement patient-safety and quality-improvement initiatives on the front end, where patients and caregivers first interact. They nod, look thoughtful and promise.

Day 951: Carlo's case has been presented at grand rounds and patient-safety conferences at the medical school. In response, studies of the handling of appointments and patient calls have been implemented.

Yet I still hear every single day of patients experiencing the same things Carlo did.

Timeline Two

Day 1: It's been a few months since Carlo died. A simple white stone now stands watch for him at Camp Butler National Cemetery.

I have put off canceling his cell-phone service as long as possible. His children, friends and family from all over the world still call to hear him say "Leave me a message," then weep and pour their hearts out into his voice mail.

But money is tight. The phone has to go. It really wasn't much good, when none of his doctors would call him on it when he so desperately needed them.

Within minutes, the phone company representative verifies Carlo's death, cancels his phone and tweaks options to reduce the bill.

Just like that, it's all done. They act like helping me with that stupid cell phone is a matter of life or death.