## *In Sickness* | February 9, 2018

## THAT'S JUST HOW MEDICINE WORKS

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My appointment was canceled again. I got another "We regret to inform you" notice. They regret to inform me that my appointment has been canceled for an unstated reason, and they invite me to reschedule in... a little over four months... after already waiting three for this slot. Seven months from my original booking. You regret to inform me.

I have a lot to say about this. First: you don't regret it at all. Obviously. If you did, you'd wish you could take it back. And of course I'd allow you to do so. "By all means, have a do-over", I'd say. Despite that opportunity, you'd stick to your decision. Every time.

This is what I've always found so insulting about rejection notices. It's not the rejection itself I find upsetting, it's the dishonesty. We regret to inform you...

I regret a lot of things. I would take them all back if I could. That's what regret means. It means you would go back in time and behave differently if that were a possibility.

What makes "I have no regrets" so insulting is that it implies you stick to your guns however badly they misfired. Your aim was untrue, you pulled the trigger anyway, and you're satisfied with your bullet's path. Collateral damage be damned; I have no regrets.

But "We regret to inform you" is even worse. Because now you're actively lying. It's not a softening of the blow. It's a poisoning of it. Without regret and seemingly without care, you inform me that I have been denied whatever admission or permission I was seeking.

When I explain to people how much of a hassle medical care has been, I only get two different responses.

One comes from everybody who is not employed by the healthcare industry, and it goes something like this: "That's unbelievable!", said in a tone that equably balances sympathy and surprise.

The other response comes from everybody who *is* employed by the industry, and it goes something like this: "Of course it takes months to get in and see these people. Why wouldn't it?"

I used to argue. "If it takes seven months to get an appointment, and the patients will be dead by then, what's the point of scheduling at all?"

What their responses lacked in reason was more than made up for in volume. And they always converged on this sentence: "That's just how medicine works."

Yes, I understand that. I understand that, in the United States of America, in the 21<sup>st</sup> century, that's how medicine currently works. I haven't failed to notice. That's also not what I'm saying. I'm saying that's not how it *ought* to work. The system is broken. And if you can't see that, you have a disability. You need more help than I do.

But let's keep the topic about *my* needs.

I've been dealing with this for 16 months. There comes a time when parents of toddlers stop counting their baby's age in months. For fear of sounding foolish, they convert to the annual system. But they still use halves. Two and a half. Three years. Three and a half. And then it's just whole numbers from there. Once parents give up the tallying of individual months, that's when, in my estimation, infants become actual people. That's the moment when one can be pretty certain this creature will be a permanent resident in the household. With illnesses, the age of years is when they, too, become permanent fixtures in your life. If you're counting the age of your illness in months, it's just a squatter. As soon as you begin tallying in years, it's given the deed to your property.

That's what I'm afraid of. I'm on the verge of forgoing my deed and I can't get the police to evict the squatter. Every phone call to my doctors and visit to the hospital is the same:

"Oh, you can no longer work or function, you're sweating profusely, your blood pressure is 170/100, you're shaking in pain, your oxygen saturation seldom leaves the 80s, and the nausea won't leave you or your toilet bowl alone? Great, we'll evaluate you in 104 days."

I don't need to explain how ridiculous this is. There isn't a doctor, nurse, or auxiliary employee anywhere who has failed to recognize that this is not how an *optimal* system of healthcare works. I get that it's how our system *currently* works. That's not what I'm arguing. "How medicine *currently* functions" and "how medicine *could* function if we valued human health and dignity" are two different conversations. And one of those conversations matters more than the other.

Let me personalize that one. Joe was our custodian. Last November, he died. I wrote a few words about it to be posted on our department's Instagram page:

🗎 instagram.com/p/Bb-9KNVgGIz/?taken-by=pacific\_hes 🛛 🛣

We are saddened by the passing of our department's legendary custodian, Joe. For those who didn't know him, he had more energy than entire fraternities on campus (probably more than most of Stockton's zip codes). And exactly 100% of that energy was kind, curious, and considerate... or about the Raiders. Someone else can change the trash and sweep up after our messes, but Joe isn't replaceable.

During Joe's last days, he and I had a lot of conversations about the medical system, mostly his frustration with the wait times. "Joe, it looks like you'll be dead in a month without proper care. We'll get you in to see the doctor in 122 days."

He checked into the emergency department long before his appointment came, shortly before he died. I visited him in the hospital that night. Hours before he died. He was lying in his bed, moaning in pain, reverting to a very sweet and sorrowful childlike state, surrounded by people who loved him. And then he passed. A couple of months later, when his appointment time arrived, some other patient took his place.

Everyone knew that would happen. Joe knew. His doctors knew. And Joe knew his doctors knew. But there was nothing any of them would do about it. The smallest gesture would have been to admit it is a broken system, and express great sympathy for his suffering. But instead, all any of us gets – Joe, me, and every other patient – is a cold dismissal: "That's just how the medical system works."

I would urge employees of this system to reexamine their understanding of healthcare and its role in society.

Compare it to any other business.

Let's say, while driving to the hospital, your tire pops. When you call to schedule an appointment, how long do you have to wait? Does your tire take seven months to repair? Does it even take a week?

I've had several flat tires. The longest I've ever had to wait was, "Is it possible to leave your car here overnight and we'll do it first thing in the morning?", when I showed up without an appointment one minute before the shop closed. "We can give you a ride home if you want", they followed up. "Nah, it's okay, I just live down the road; I can walk", I said. The next morning, when I woke up, I walked back to the shop and my car was ready.

That sort of sympathy is unimaginable in healthcare. And this was just a tire. An old, worn out slab of rubber. It's not a human being, in pain, terrified, confronting mortality. It's a tire. Yet, somehow, I've never met a doctor who could compete with a mechanic in sympathy, urgency, or decency. If you want to experience tender customer service (i.e., bedside manner), go to the auto shop. You won't find it in healthcare. Not even DMV is as mismanaged or frustrating as medicine. In my experience, the efficiency of action and customer-oriented nature of DMV inspires awe by comparison. Same with the police, AT&T, Walmart. Complain as much as you want about your cell service or the sticky wheel on the shopping cart at Safeway, but you know American medicine is a disaster by comparison to any of these industries.

The police seem to get the most criticism, so let's start there.

And let's begin with a hypothetical scenario:

It's Monday morning at 9am. A little bit rainy. The local Bank of America just opened. Three men wearing Teletubbies outfits barge in, pointing guns at the tellers and yelling conflicting demands: "Nobody move!" and "Hands up!" and "Put the money in the bag!" One confused teller attempts to obey all three commands and is shot for his disobedience by all three men. Another teller reaches under the counter and pushes the panic button, alarming the police that a robbery is currently in progress. It's important to notify the authorities as quickly as possible because it will take the officers approximately 14 weeks to arrive.

Or how about we compare doctors to firefighters. Let's say your house is burning down. Every minute without intervention permanently consumes more of your home and its contents, your life and its memories.

You call the fire department and frantically explain that your attempt at celebrating Guy Fawkes Night got out of hand.

"Okay, calm down. We'll come put the fire out in three months with a 50% chance of cancellation, but when you reschedule, it's likely to only be 40 to 50 additional days."

"But everything I own will be completely consumed in 20 minutes."

"If there's a cancellation, we might be able to schedule you sooner. Feel free to call next week and check."

"But... I... I can't wait that long."

"I feel like we're talking past each other. That's just how the fire department works. Why wouldn't it?"

Okay, I'm done writing. I'm squinting at my screen because I'm experiencing what feels like an ice cream headache at its peak, piercing my skull for the fourth unevaluated week. Because that's just how medicine works. Obviously. Why wouldn't it? I'm not a tire.

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