

ALSO BY SARAH MANGUSO

The Captain Lands in Paradise

Siste Viator

Hard to Admit and Harder to Escape

The Two Kinds of Decay



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PICADOR

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Some names and details have been changed.

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The Beginning

The disease has been in remission seven years. Now I can try to remember what happened. Not understand. Just remember.

For seven years I tried not to remember much because there was too much to remember, and I didn't want to fall any further behind with the events of my life. I still don't have a vegetable garden. I still haven't been to France. I have gone to bed with enough people that they seem like actual people now, but while I was going to bed with them I thought I was catching up. I am sorry. I had lost what seemed like a lot of time.

I waited seven years to forget just enough—so that when I tried to remember, I could do it thoroughly. There are only a few things to remember now, and the lost things are absently, comfordingly gone.

I wrote down some things while the disease was happening—there are notes from one hospital stay and a few notes from the sickest years—but it isn't much.

Sometimes I think the content of those days might not have finished happening. It might have begun then, in 1995, but I needed to save the rest of it until I was stronger.

The events that began in 1995 might keep happening to me as long as things can happen to me. Think of spacetime, through which heavenly bodies fly forever. They fly until they change into new forms, simpler forms, with ever fewer qualities and increasingly beautiful names.

There are names for things in spacetime that are nothing, for things that are less than nothing. White dwarfs, red giants, black holes, singularities.

But even then, in their less-than-nothing state, they keep happening.

Allegri

I sang in a choir and took good care of my throat, and when I caught a head cold in February 1995, during my junior year of college, I took tea and herbal lozenges.

I liked that our British choirmaster didn't accept a head cold as a valid excuse for missing a rehearsal.

We took our duties seriously, for in serving our duties to the Memorial Church we might achieve excellence, which many of us valued above the other virtues.

I sang second soprano and I wasn't fearless, so I chose only a few solo auditions per year. I sang the second soprano solo in Gregorio Allegri's "Miserere," a setting of Psalms 50 and 51.

The piece was composed in the 1630s and has nine parts and is sung by three choirs standing in different parts of the church. When we sang it, the plainsong choir stood in the balcony, the solo choir stood behind the choir screen, and the rest of the choir stood before the congregation.

Bad Blood

I was brought upstairs from Emergency to Intensive Care and given a treatment called *apheresis*.

From the Greek *aphairein*, to take away.

In the hematological context, apheresis is the process of separating blood into its components (red cells, white cells, platelets, plasma), removing the component that's sick, and reinfusing the rest of it, along with a suitable replacement for the sick part. The sick part of my blood was the plasma.

My nurse told me about a man she treated whose body manufactured too many platelets, enough to clot his blood right in his blood vessels. And so when his blood was separated, the extra platelets were removed and thrown away, and replaced with saline to make up the lost blood volume.

I thought his platelet-producing powers might have been made useful—if his extra platelets could flow out of him, through an apheresis centrifuge, and right into a hemophiliac.

But of course the man's genes might have been diseased, or he might have been infected by a secret virus, and his platelets might have given someone his disease, or worse. So they were just collected in a bag and thrown away.

My plasma was filled with an antibody that destroyed peripheral nerve cells, so it was thrown away, too.

My plasma was replaced more than fifty times, and the effects of the treatment lasted as long as the fresh plasma stayed clean of the antibodies, which for several months was only about two days.

The machine took four hours to clean my blood. I bled eight ounces into the centrifuge, then the machine spun the blood fast enough to separate it into four layers. My plasma flowed into a bag, then my cells were mixed with saline, synthetic albumin (a blood plasma protein), and fresh frozen plasma, which contained the other plasma proteins. That new mixture was reinfused. And then the machine withdrew another cup and did the same thing, and then another cup, and so on, until the new plasma occupied enough blood volume that it was no longer useful to withdraw and clean another cup.

The first twenty times or so, before I had a central line—a tube in my chest that provided easy access to my blood—my arm veins were used for blood collection and reinfusion.

I received direct injection, via tubing connected to a *cannula*, or hollow needle—no flexible catheters were inserted. I had to lie still so the needles didn't tear my veins. Fourteen-gauge

needles were used, large enough to keep my healthy cells intact so they could be reinfused. There was one in each crook of my elbow—one to take blood out and one to put it back in.

It is not easy to lie still with a fourteen-gauge needle in each arm, for four hours, shaking with cold that doesn't go away no matter how many heated blankets are tucked over you. The cold comes from the inside.

By comparison, routine blood draws, which I had several times a day, are taken via twenty-gauge cannulae, and infant lines are usually twenty-four-gauge. Twelve-gauge and fourteen-gauge cannulae are the widest used and deliver fluid faster even than lines that go to the heart, and are also known as *wide bores* or *trauma lines*.

Over time, the blood draws felt good. My veins were always in the process of healing from multiple punctures, and the tiny twenty-gauge prick scratched the itch that comes when flesh heals.

I bled out two liters of plasma during each treatment, but I was always given back more than two liters of fluid to prevent dehydration. Two liters of albumin, about a quarter liter of fresh frozen plasma, and some saline. I let my bladder fill as full as I could, but sometimes I had to raise my hips so someone could slide a pan under them for me to piss into.

The nurses always congratulated me on my impressive bladder volume. I once pissed 900 cc. That was my record.

The waste bag hung on the side of the machine and filled slowly with my yellow plasma. Periodically I'd ask the nurse to hold up the bag so I could see how full it was. It felt warm, like a bag of soup. By the end of each treatment, the small empty part left at the top of the bag would be clouded with condensation from the almost hundred-degree fluid.

One day during the treatment I was hungry and ordered a plate of french fries from the cafeteria. They were delivered, and I ate them during the treatment. This was later on, after my arm veins had scarred and after I had a central line in my chest, which left my arms free to move.

After that treatment, the plasma in the waste bag was pale and cloudy. The nurse and I realized I'd digested the french fries as my blood was being cleaned, and that the lipids from the french fry grease had been digested, released into my plasma through my small intestine, and then bled out into the apheresis machine.

After we figured that out, I ate french fries every time my plasma was replaced. My nurse and I imagined that in the future, people would have their plasma replaced whenever they ate rich meals.

Apheresis did a good job of cleaning out the mess in my blood, but since it only removes the antibodies once they're secreted into the blood, and doesn't prevent the body from making more, apheresis wasn't a permanent solution to the problem of my disease.

Metaphors

My blood plasma had filled with poison made by my immune system. My immune system was trying to destroy my nervous system. It was a misperception that caused me a lot of trouble.

All autoimmune diseases invoke the metaphor of suicide. The body destroys itself from the inside.

I secreted poison into my blood. The poison was removed and replaced with other people's blood and with chemicals.

With my own blood in me, I couldn't feel, and I couldn't move, but with other people's blood in me, and with chemicals in me, I could do those things.

The new blood became mine as soon as it entered me. Or maybe it took a moment to mix with what was there. Or maybe it took an hour, or a day.

My blood came out dirty and went in clean. It came out hot and went in cold. It came out old and went in new.

And the new, cold, clean blood was better than the blood I made myself.

Names

The first doctor known to have observed cases of my disease was Jean Landry, in 1859. He saw that his patients initially began to feel numbness and paresthesia (abnormal sensations) in their feet.

In addition to the strange sensations and numbness, the patients' feet grew weak and then paralyzed. And the numbness and paralysis spread upward from the feet, up the legs, and then continued up the torso to the diaphragm. When the diaphragm muscles weakened to the point that the patient could no longer breathe, the patient died.

And so the first proper name of my disease was *Landry's ascending paralysis*.

In 1916, two more French doctors, Georges Guillain and Jean Alexandre Barré, studied several people with ascending paralysis and observed the key diagnostic abnormality of increased spinal fluid protein but normal cell count.

And so the second proper name of my disease was *Guillain-Barré syndrome*.

The pathology is now understood as the immune system's generation of antibodies targeting the peripheral nerves' myelin, their protective and conductive protein sheath.

Landry's paralysis came from nerves that had lost their myelin. And the protein in Guillain and Barré's spinal fluid was made of that stripped-off myelin.

The condition may resolve spontaneously, relapse and remit indefinitely, or progress and terminate in death.

In 1998, after my first year of graduate school, I put on my MedicAlert bracelet. It's engraved:

TAKES PREDNISON FOR
CHRONIC IDIOPATHIC
DEMYELINATING
POLYRADICULONEUROPATHY

Chronic idiopathic demyelinating polyradiculoneuropathy. CIDP. That's the shortest name for what's wrong with me. It's something like a chronic form of Guillain-Barré syndrome but not exactly, and there isn't a proper name for it yet.

Statistics

Approximately 80 percent of Guillain-Barré syndrome patients have a complete recovery, and about 10 percent recover with severe disability, though the death rate among patients is still about 2 to 3 percent even in the best intensive care units.

It's hard to project these data onto my disease, CIDP. My disease is similar to but not the same as having Guillain-Barré syndrome over and over again, with no time to recover between bouts.

Some believe the clinical difference between Guillain-Barré syndrome and CIDP is subjective—that my disease was CIDP because I was sick for years instead of just a few weeks. Sometimes I think I might just have had a particularly bad case of Guillain-Barré syndrome.

Of course I'd rather have the common disease that people know how to treat, but there were times that I cherished my rare disease for its irrefutable proof of my specialness.

For its proof that my death, the end of the disease, whenever and in whatever form it came, was going to be remarkable.

Causation

Was the CIDP a physical manifestation of a spiritual illness?

Did the medication trigger the depression, or did the depression trigger the CIDP?

What about those yogis who can lie down on a bed of nails, then arise, streaming blood, then stop the flow of blood from each wound individually with the power of their minds? Isn't frailty often a choice?

And if frailty is a choice, then isn't an autoimmune disease a semi-intentional suicide?

What came first, the suicidal depression or the suicidal autoimmune disease?

Did they happen independently of each other, or not?

Sometimes I think that in the real universe, I am born already in possession of my CIDP, my depression, my whole life and death, and the text of this book. That I'm incapable of making

the events of my life happen—either because they've already happened, or because they're always happening, at every possible point in spacetime.

And then sometimes I think I've made everything happen, starting with making myself be born.

The Internship

When I was sixteen, I was a volunteer intern at the local hospital.

I was given a white coat and a clipboard and accompanied the medical students on their clinical rounds.

I scrubbed in and watched vascular and orthopedic surgeries not knowing that in the future I'd have both kinds.

For several weeks in the pathology labs, I made slides from tissue samples suspended in wax.

One day a doctor and I visited a patient who was deeply asleep. She was an old woman, and her name was Anna.

I held Anna in my arms as the doctor listened for her breaths through a stethoscope held to her back. She wasn't cold or waxy or lying in a pile of excrescence, so we spent a long time trying to find a pulse. She looked no older or frailer or sleeper than many of the other elderly patients.

I watched her clean up messes that horrified me, and she was cheerful, always.

One day she told me about the phlegm that formed in cancerous lungs. Sometimes she had to suction that phlegm. And sometimes it was black with necrotic tissue.

The young nurse said she'd never got used to the odor of that phlegm.

Sometimes I could hear people being suctioned. And sometimes above the slurping sound I heard the people yell in pain or in fear at seeing their own dead selves being sucked out of them.

The Wrong Symptom

The nerve damage associated with my disease is supposed to begin at the toes and move upward, as if you're sinking in invisible, numbing quicksand.

Or sometimes it begins at the hands and moves up the arms to the torso—as if you're standing in the quicksand on your hands.

During one of my hospitalizations, after being pricked with the pinwheel—a metal tool resembling a pizza cutter—I reported a spot of numbness on my abdomen. It was, coincidentally, about the size of a slice of pizza. The numb spot was surrounded by flesh that could feel. And that symptom wasn't clinically normal for someone with my disease.

There was no diagnostic explanation for that numb spot, and so the following explanation was given: while there may in fact be a symptomatic area on my abdomen, the symptom I was reporting was not the correct one.

In my disease, the numbness starts distally, in the toes and fingers, and progresses proximally, toward the trunk. In my disease, there are no numb spots on the trunk. Those neurons aren't stripped of their myelin until the arms and legs go numb first.

After considerable discussion among the doctors and their entourage of students, it was declared that I had indigestion, which was common in patients who had been lying on their backs for days or weeks as I had, and it was declared that since I was used to reporting all symptoms as numbness, I was feeling heartburn and reporting it as numbness.

If I broke a toe or lacerated my palm, it was apparently assumed I'd report the pain as numbness because I'd become accustomed to calling my discomfort *numbness*.

A doctor listened to my belly through his stethoscope and declared gastric unrest, though there is always some unrest in the bellies of the living.

I was prescribed a few tablespoons of liquid antacid. I drank it and the symptom abated a little, maybe.

And so the sensory changes had been caused, of course, by the antacid, just as the symptom had been caused by indigestion, and just as the indigestion had been caused by my having lain on my back for so long.

But not really.

Bananas

The next time you have some sensory nerve damage, touch the paresthetic skin and evaluate its numbness.

Wait a minute. Then touch the skin again.

Wait another minute, then touch it again. Again. Wait an hour. Two hours, ten hours, a day, two days.

Is the numbness changing? Getting bigger, smaller, stronger, weaker? What have you done in the last four days? Sometimes potassium deficiency causes paresthesia. Have you eaten many bananas in the last four days? Go to the store and buy six bananas and eat them in the space of a morning. And feel that, yes, the numbness is disappearing! Since digesting most of the six bananas, your hands now feel a softer version of the soft quilt you have been lying under!

The world, with its infinite variables, is the wrong place to attempt implementing the scientific method. Most successful experiments work only in vacuums. Boyle's law, Newtonian mechanics—only in vacuums are they true.

Narratives in which one thing follows from the previous thing are usually imaginary.

Everything that happens, happens in a moment that follows from all the other moments in spacetime.

As I see it, that's the main problem with neurological symptoms that can't be measured in numbers yet, and why many of my symptoms weren't treated.

Those symptoms weren't treated because they were unlikely enough to be virtually impossible. My reports of them were their only observable evidence.

My symptoms were so unlikely, by the book, that despite my reports of them, they were assumed not to exist.

Strength

After my first hospitalization I was sent home with a prescription for three physical therapy sessions per week at the local rehabilitation center. I was all better.

My physical therapist asked me what I wanted to be able to do, and I tried to think of the hardest thing I'd been able to do before I'd got sick. I said *run three miles*.

The therapist knew how to strengthen each muscle that had been weakened by the rogue antibodies in my blood, and she took a few minutes to record the strength of each muscle and to write a detailed plan, and then she explained the plan to me.

All I remember of her plan is that she pronounced the word *strength* as *sh'trenth*. Over and over.

I got on the treadmill, but I had foot drop—my feet slapped down because I was too weak to dorsiflex, to turn my ankle and toes upward—and so I stomped with flat feet. Marched. And tripped a lot. I was going one mile per hour. The first day, I walked for five minutes. Eighty-three thousandths of a mile.

So the lidocaine began to wear off, and the doctor kept telling the interns and the surgery residents exactly what the trouble was, and he became frustrated when he couldn't get the tube into me, and tried another, thinner tube, and sweated onto me, and stunk up the entire room with his frustration.

He tried again and again to jam the tube into my vein. Every now and then he had to stop and apply pressure, as I was bleeding. At one point I thought I felt a jet of blood spurt into my chest cavity, and that's when I lost my composure.

Months later, after his hair had gone from steel gray to white, my father told me it had looked like a horror movie.

The Taste

The fresh frozen plasma was thawed before it was infused. The four half-liter glass bottles of albumin were left at room temperature.

For the first twenty or thirty apheresis sessions, I lay under several blankets, which didn't help the cold but helped me think at least I was trying.

The temperature in blood vessels is warmer than room temperature, of course, by about thirty degrees Fahrenheit. I was very slowly infused with several liters of fluid that was thirty degrees colder than the rest of my body.

By the time I had the permanent line, the cold infusions went in very close to my heart. I need to describe that feeling, make a reader stop reading for a moment and think, *Now I understand how cold it felt.*

But I'm just going to say it felt like liquid, thirty degrees colder than my body, being infused slowly but directly into my heart, for four hours.

The albumin had a taste. To be more specific, the albumin had two tastes, because the hospital bought albumin from two different manufacturers.

Both companies used the same 500 cc clear glass bottles, which were sealed at the narrow end with rubber drums that could be sterilized and punctured with sterile needles and connected to sterile tubing.

One company's albumin was the color of light beer and the other company's was the color of lager. And the dark albumin tasted worse.

I never could decide whether it was *chemical* bad or *organic* bad.

I had to taste it for three or four hours, unabatedly, and there was nothing I could do to change the taste of it. It wasn't touching the surface of my tongue, but it was going into the blood in my heart, which pumped it into every cell in my body. It was *in* my tongue.

The only thing that masked the taste of the albumin was wintergreen-flavored candy.

Tabitha, my favorite apheresis nurse, always arrived with a bag of wintergreen candies, individually wrapped. She picked them out of the mix for me—there were red and yellow and purple candies, too, and different kinds of mint—and left a small pile of them behind, because the taste of the albumin lasted for a while after the infusion was over, and she wanted to make sure

I had enough wintergreen to get through the rest of the day without having to taste any albumin. Without that reminder of how I'd spent the morning.

Tests

First you'll feel a tiny sting where the needle goes into the lumbar spine, then a small burn when the anesthetic is pushed into the tissue, then a bit of pressure when the second needle goes in, and then nothing. You'll just lie there on your side, fetal, and if an intern or a student gets to do the puncture, you'll hear everyone congratulate the intern or the student once the fluid is in the test tube. And if you ask to see your spinal fluid, someone will hold up a test tube of perfectly clear fluid.

And then everyone's happy and you'll just lie flat awhile until there's no risk you'll get the notorious spinal-tap headache if you move.

You can rest knowing it will be days before you'll hear whether the fluid contains a high protein content yet a normal cell count, the combination of which indicates severe nerve damage.

These days, hospitals have open MRI machines, but my hospital had only the closed kind. If you needed an MRI taken of the top of your neck, you were slid all the way inside the machine.

Once you're inside, it's hard not to notice that the wall of the hollow tube is no more than six inches away from your body at any point.

My muscles were atrophied when I had my MRIs, and I was very thin. If the walls had been only six inches away from my body, a larger person wouldn't have been able to fit into the machine. So this memory must not be right.

But the point is that once you're inside, if you have any imagination at all, you feel as if you have been buried alive in a white plastic coffin.

This is why MRI technicians offer a slight sedative before the procedure, and why they say to keep your eyes shut and imagine that the thudding sounds of the machine are waves crashing on a beach, and why they speak to you throughout the test, asking how you're feeling and declaring that you're doing well, and why they place a panic button in your right hand. If you press it at any point, they slide you right out of the tube.

If you think you might open your eyes inside the tube, ask for a washcloth to be laid over your eyes. It will work as a blindfold, even if you open your eyes underneath it, and since you're in a coffin, you can't move your arms or any other part of your body to touch the blindfold, and you will not be afraid.

More Tests

For a nerve conduction velocity test, electrodes are stuck to the skin above the tips of the neuron in question. Then electric shocks are delivered directly to the nerve cells. You lie there and get shocked. You know the shocks are coming. It's simple.

The shocks start small and get bigger. There is a break of one second between one shock and the next.

For the first few series of shocks, you think it wasn't so bad. Even the strongest shock isn't enough to make your whole body seize. If it's a leg nerve that gets shocked, the biggest shocks will only make your leg thrash.

That's the whole first part. It lasts an hour or less to test three or four nerves. And while the discomfort is unrelenting, the pain is not excruciating.

An electromyogram is more or less the same—electrodes delivering shocks—but with sensor needles in the muscles that those nerves innervate. So it's the same shocks, but you must

keep the muscle tense while the shocks are delivered to the nerve cells and while a needle is jutting out of the muscle.

The technicians always ask whether it's your first EMG. If it is, they say it's all right to cry. And maybe they'll add that men cry more than women, or that a great big juiced-up guy from South Boston is more likely to cry than a librarian from North Cambridge. Or that people who try hard not to cry are more likely to cry than people who are open to the possibility that they might cry. The EMG technicians watch people get tortured all day, but it is hard even for them to guess how anyone will hold up until the actual breaking point.

I got through my first three EMGs without crying. Each one got easier.

But then one day, when there were no lab technicians available, a doctor administered my EMG. He could deliver the test as well as interpret the results, right there, while the data from the first shocks showed on the computer screen.

And I asked him what the data looked like, and he said the data looked bad. My nerves' conduction velocities were slower than they'd been the last time, and their conduction block had increased. The antibodies had destroyed more myelin.

And right away I knew I would need to get a new central line implanted and have my plasma replaced again, and I also knew that each time the myelin was stripped from my nerves, it was likelier to grow back imperfectly, and that I was likelier to lose strength and sensation permanently.

It wasn't the EMG but the bad news that made me cry. It's probably best to have an EMG while someone's opening your mail and finding that you got into college, or while you're watching the right lottery numbers appear on the television screen.

If you start crying during an EMG, you can pretty much forget about trying to stop crying until the test is over.

I'd guess that if you get a dozen EMGs in your life, it's likely you'll cry during at least one of them.

I don't know any other hospital procedure that makes people cry as reliably as an EMG except the test of the blood's clotting agents, when you just sit and bleed from a puncture wound, and the blood drips until your fibrinogens and platelets create a barrier to the bleeding, or it's decided you've lost enough blood that it's certain your fibrinogens and platelets aren't going to be able to stop the blood, and then the test is over.

Tabitha

Tabitha called nail polish *nail enamel*. Her daughter was ten or fifteen years older than I was. The daughter had lived out of her car for a long time.

Rock and roll, I said after Tabitha told me that. Living out of your car was cool. It wasn't even her car. It was her boyfriend's car.

Tabitha never scolded me for saying stupid things. She told me her daughter had a skin-picking problem. Lesions on her face.

Lesions?

Just acne. Small inflammations. Tabitha liked using the proper medical terms for things. She told me the story of her first day of nursing school. She'd already read the text for the week ahead, and when the professor asked what *p.o.* meant in a clinical context, Tabitha said she raised her hand and said *per os*, by mouth, as if it were nothing at all. Rock and roll.

Tabitha manipulated the hell out of that apheresis machine. I hardly shook.