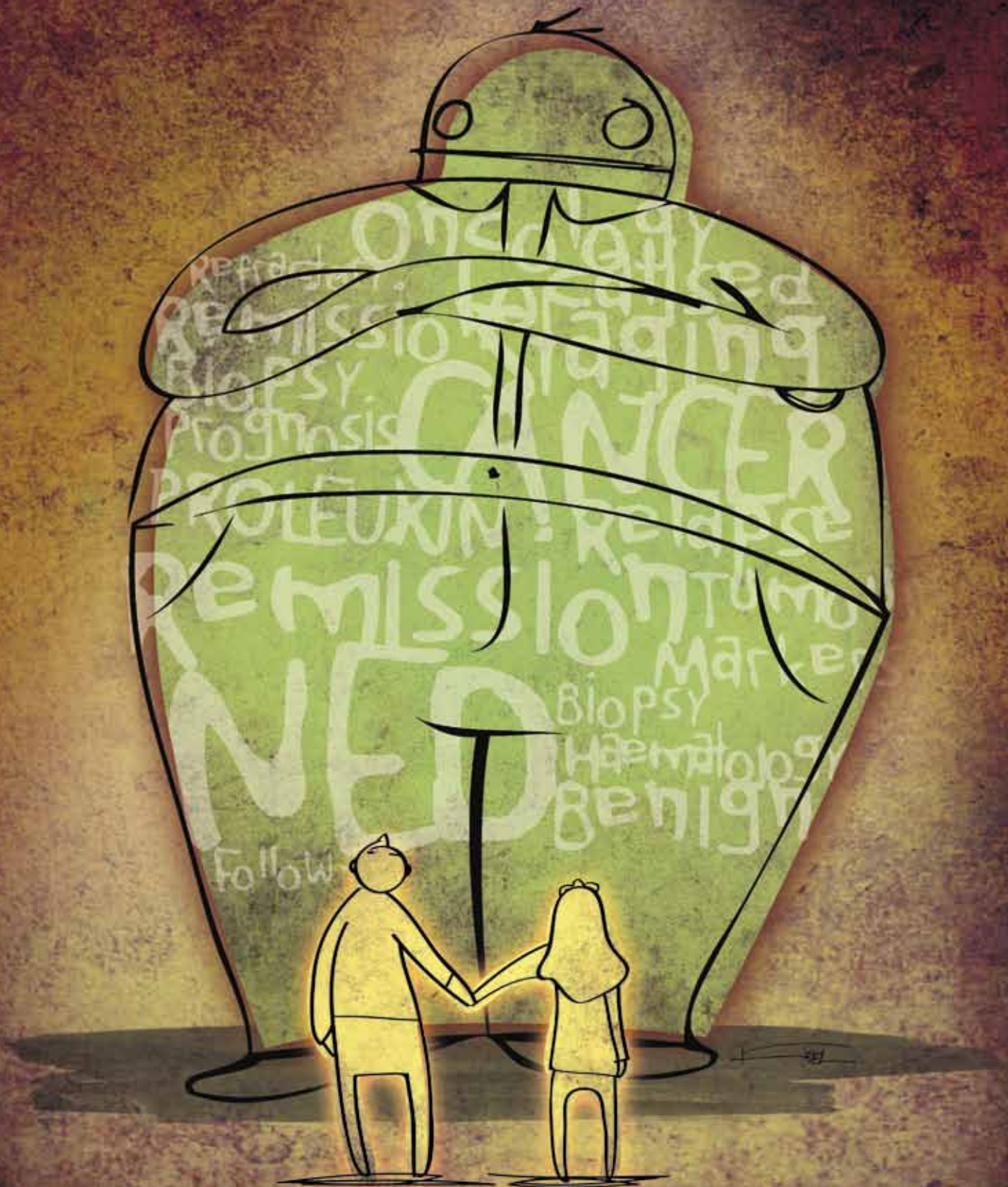


# The **FAT MAN** of Cancer

FACING CANCER, A FORMER ARKANSAS JOURNALIST EMPLOYS A NEWSMAN'S INSTINCTS TO FIND A CURE: TRUST NO ONE, ASSUME NOTHING, GET THE FACTS.

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**I**f you're going to be killed, it may as well be by your doctor. In the beginning it did not occur to me to question my doctors. When I first limped into the emergency room precious little entered my mind at all save the paranoid fear that my wife had slipped carburetor fluid into my cereal. My insides were writhing. I was a little unhinged. My scalp wet with sweat. I did not dismiss the idea that a vicious little man, preternaturally tiny at birth, had crept into my small intestines and was attempting to wrench the juice out of my appendix for some kind of exotic cocktail.

With a CT scan in hand, the emergency room physician assured me that there was neither man nor beast gorging on my internal organs. It was something else. It was me. It was rebellious cells of my

own making gone mad with ambition, attempting to create entirely new organs of unknown evolutionary purpose.

"You have a tumor in your kidney," he said. "About the size of my fist." He held up his fist.

He was a large man. "The kidney needs to come out immediately."

The rainbow of pain meds did soothe the holocaust in my abdomen but did little to ease my paranoia. Who says such things to a guy when he's already down? Was he harvesting organs for the Chinese black market? Could I trust a man in a white coat and receding hairline?

And another thing — did this guy just tell me I had cancer?

## DIAGNOSED — AND CURED

Yes, it was cancer. An uncommon cancer known as Renal Cell Carcinoma.

And the kidney came out. Immediately. It was sent to a lab and probed by a pathologist and never seen again. It is probably rotting in some nuclear dump in Arizona. Or sold to some unsuspecting sucker in China. In any case, I was free of it. And free of cancer, I was told.

"You are cured," my urologist told me after he had completed a scary-sounding surgery called a radical nephrectomy. Radical times, however, call for radical measures, and we had succeeded. Visibly proud of his handiwork, he provided color commentary on how he had sliced two small openings on the right side of my torso and inserted an incomprehensible array of long-necked tools through them, along with a bottle-necked camera, and performed the entire procedure by watching a video monitor as if he were catching the news on CNN.

His surgical grace and acrobatics were lost on me, however. All I heard was: You're cured. Almost as an afterthought, he suggested I return in six months and do an x-ray. I registered, somewhere in the spideriest corner of my compartmentalized mind, a red flag. If I was cured, why come back for x-rays?

So I did the very thing that doctors universally urge us not to do. I went online and began medigoogling to learn whatever I could about my new nemesis. There's a lot of misinformation online, with some pretty whacked-out suggestions for alternative remedies. For example, ingesting mega volumes of bird guano may not be as reliable a cure for migraines as you might think. I also learned, however, that there

was a reasonable chance the cancer might return and, if it did, if it metastasized and splintered, if the napoleanesque little things resumed their grim march in search of new organs to conquer, the survival rate of somebody in my condition was bleak indeed.

I called my wife, Dena, at her office and informed her of my findings and she went quiet and then she went incoherent and then she went temporarily insane. We don't speak about it. Its legend has grown, become apocryphal. There are whispers of her tearing wall sockets from floorboards, emasculating male colleagues with a rusted paper weight. Windows smashed, supervisors fleeing shirtless into the streets.

Whatever happened that day, she came home early with a newly acquired prescription for Xanax and descended into a crazed binge of research, an addict in the throes of overdose, sleepless and eye-weary. When she resurfaced she did so with a shiny new degree in oncology from Google U.

"We need a new doctor," she said. I was startled by the authority with which she made this mutinous assertion. I was hesitant to question a man who had, probably, gotten his degree from a real university. "He's a urologist," she said. "He knows just enough about kidney cancer to make him dangerous."

However, I was not about to cross my wife. I still harbored suspicions about her affinity for carburetor fluid. So, we went to see another doctor — this time a urologist specializing in urological cancers. He seemed impressed with the size of my tumor. "This thing has probably been growing inside you for close to ten years," he said. I tried to walk this back in my mind. It had been with me through at least five different jobs and traveled with me from a newspaper job in Little Rock to Washington, D.C., back to a political job in Little Rock and D.C. again. It was probably my oldest friend.

And then he suggested that, yes, x-rays every six months would be adequate. Dena immediately tossed him into the ashheap of discarded urologists.

"Six months and an x-ray won't do," Dena told me outside the doctor's office. "We need CT scans every three or four months. No more urologists. We need an oncologist, a real one."

Six months and an x-ray won't do, our new oncologist told us. He recommended a regimen of CT scans every three months.

Right before me, Dena's brain grew a pound. How could she have known this? It was at this time that I began to seriously consider the possibility that she might be a witch.

Our oncologist was surprised when we told him that I was supposed to have been cured. "There's no such thing as a cure," he said. Even five years ago there was little that could be done for somebody with kidney cancer. "My job was to help you die,"

he said. This casual statement, almost an aside, a 180 from "you're cured," stunned my brain physically. He looked up from his charts. "There's an array of new drugs developed and approved in the last several years, though. We have options now."

While there might be no cure — he used air quotes to emphasize this point — we could strive for NED. NED is not some crazy overweight uncle from Ohio but the condition of showing No Evidence of Disease. It's like purgatory for cancer survivors — not cured but not dying but somewhere in between.

## BEDIAGNOSED — AND NOT CURED

Just three months later Dena and I sat waiting to see the results of my CT scan. The oncologist's assistant entered the room. At least he claimed to be the oncologist's assistant. Balding guy. White coat. Clipboard. He fit the profile.

"So," he asked. "Have you had a cough lately? Any shortness of breath?"

"No."

"Huh. Well, you've got spots in your lungs."

"Spots?"

"Likely mets. Metastasis."

When cancer spills into the bloodstream and begins snorkeling through your veins, you are immediately vaulted to what is known as Stage IV cancer. Another term of endearment is metastatic cancer. Both phrases are politically correct — and medically correct — alternatives to the dreaded phrase terminal cancer. In my mind, though, this man had just given me, at what I liked to believe was the still tender age of forty, a death sentence as casually as if he were offering me a glass of wine.

There was a long and awkward silence which he did little to fill. For some reason, all I could think about was how prescient Dena had been about needing CT scans every three months. This settled it; she was definitely a witch.

"We need to get you set up on chemotherapy," the balding man with a white coat and a clipboard said. (I am no longer certain he was an oncologist's assistant.)

Dena nearly stabbed him in the eye socket with her car keys. "I don't think so," she said. "Chemotherapy doesn't work on kidney cancer."

An awkward pause.

"I'm sure all of this is a shock," said the white-coated man. His was the kind of slow, parched voice you might use during an encounter with a rabid dog. He probably didn't even believe in witches, and yet here one inexplicably sat in his examining room, challenging him, clearly not afraid to gouge out his eyes. He left abruptly.

Our oncologist entered somewhat warily and acknowledged that chemo was not the right course of treatment. My situation was inoperable, he added, and he wanted to start on the drug Sutent right away. Sutent is one of the new wonder drugs of kidney cancer. It can potentially "extend life" for several months or several years, but it can't usually offer up the holy fat man named NED. There is only one treatment that can — one that our oncologist seemed oblivious to. This treatment — High Dose Interleukin 2 (IL-2 in hospital lingo) — is NED made manifest. And taking Sutent would undermine or block outright our ability to undergo this treatment.

Thank goodness for my witch. I would have simply saluted. Dena, a contrarian by nature, doesn't do such things. At home, this is annoying; at the doctor's office it is a godsend. Her annoyance with his recommendation was obvious in the way she white-knuckled her car keys, still gripped in her small hands like a weapon. When she spoke, however, her voice was restrained. She said she wanted to wait on the Sutent and try IL-2 first.

Our oncologist seemed stumped. A dialog bubble seemed to appear over his head: What is this IL-2 thing of which you speak? I wondered if he could feel Dena's Wicca eyes on him.

"Well, that is very toxic, very hard on the body," he said finally. "And few patients have success with it."

Indeed. The warnings on the website of the drug, named Proleukin on the market, read like a chart in the medical examiner's lab:

*PROLEUKIN® administration has been associated with capillary leak syndrome (CLS) which results in hypotension and reduced organ perfusion which may be severe and can result in death.*

Some people get a rush from rock climbing or skydiving. I get one from reduced organ perfusion and extravasation of plasma proteins. Besides, our desire was not to "extend life" for a couple of years but to sweep the cancer from my body. Low chance of success or not, I wanted NED, man. And only Proleukin could deliver him to my door.

And so we found ourselves on the hunt for another doctor. Again.

This time we would find a renal cancer specialist no matter what it took. Our search was like deciding on a college. We called hospitals and interviewed doctors — including an old elementary school friend who was now a prominent oncologist at Duke's Comprehensive Cancer Center; she would become my closest informal advisor. We spoke to other kidney cancer patients, mapped out road trips and tallied travel costs. Coming to grips with the myriad insurance rules was a bureaucratic Rubik's Cube.

In the end, we selected Duke. It was south instead of north, which as a lifelong Southerner seemed comforting and unfreezing. And the renal specialist at Duke was on the cutting edge of kidney cancer research; he knew about IL-2, he knew about Sutent, and he knew about a wide array of other experimental treatments we'd never heard mentioned.

## THE SEARCH FOR NED

I've now completed fifty-one doses of IL-2 over the course of seven months and it has indeed had its tribulations. I have hallucinated snowy owls in my hospital room. My feet have ballooned into clown's shoes, swollen and discolored from edema. My skin has burned red and peeled, like a college drunk asleep on the beach under a smoldering sun. I have collapsed and subsequently been Scarlet Lettered with "Fall Risk" accessories and bracelets. I have had pains in my joints so severe that I am certain vengeful nurses kneecapped me in my sleep. Near kidney failure. Collapsed blood pressure. Catheters in uncomfortable places. But under the care of Duke's experienced staff and strict protocols, carried out under intensive-care conditions, none of the chilling potentialities listed on the Proleukin site became reality.

The treatment did not eliminate the cancer from my body, but it killed off many of the smaller mets shotgunned in both lungs and stopped the rapidly growing larger ones in their tracks. It has opened the way for lung surgery, an option I was previously told was impossible.

We had come a long way in fifteen months. If we had stuck with my first two doctors, I might not even know of the metastasis to this day. Had I stuck with the third, I may have been denied the option of IL-2 and surgery. In short, had I listened to my doctors instead of my witch, I might be dead.

Having finally found the right doctors and nurses, though, I am confident that medical science and spousal sorcery will bring NED to my door. And when he comes knocking, I plan to let that crazy sonofabitch in, offer him a bourbon, and entice him to stay a long, long time. 🍷

