

Dr Tinsley-Vance's Patient with Myelofibrosis

Twelve years ago, Jim told me that I needed to cancel a grizzly bear photo safari to Alaska. He said he just couldn't do it. He told me he had an appointment with an oncologist.

"A what?"

"An oncologist."

"That's a cancer doctor?"

"Yes it is. I have cancer."

"Whaaaaaat?"

"Yea, you know those drugs I took off and on (Hydroxyurea) that was for the cancer."

"You should have said something."

"It wasn't an issue. Now it is. You can go to the oncologist with me if you promise not to cry. If you cry, you can't ever go again."

So we went, though I'm crying now remember that day, that discussion.

We went to see the oncologist and I heard what he had to say. He was pushing hard for a splenectomy, though Jim's spleen wasn't huge. We asked about clinical trials. We asked about Jakify. The doctor was adamant. NO.

On the way home I begged Jim to call Moffitt. The doctor was dead set against a second opinion. Jim finally made the choice to go to Moffit. I still have a recording of that very first meeting with Dr. K.

Dr. K tried to talk to the other doc who was dead set against the Jakify clinical trial. We never saw him again. In June 2012, Jim became a Moffit patient.

Jakify quit working after about three years.

Another clinical trial.

And another.

There was one drug that did well, but the company had financial issues and discontinued the medication. We were driving when Moffit called with the bad news. We were disappointed.

Another and another.

The one that I remember most is the Thalidomide. Jim had to wash his hands after taking it. I was instructed not to touch it.

Then another.

And a rework of Jakify.

And his spleen kept growing.

Jim often invested in the companies producing the magic drug. Since I don't own any pharmaceuticals in the last year he must have divested all of them.

He just rolled with it, though, our lives were tied to Moffit. We could go on brief trips to Sarasota or other close locations, but we stayed close and just managed.

Over the years, our lives got smaller and smaller. I'm 15 years younger so while our time together was good, it was full of accommodation.

His spleen kept growing. After Jakify none of the meds did much for his spleen.

The last three years it became obvious that the disease was taking its toll. There were one or two hospital stays a year.

The spleen was so big it caused a hernia. He dealt with it for a few months. Saw two surgeons who said it was a life-threatening surgery. He found a hot shot in Sarasota who said, "What's wrong with those guys?" THAT is what you want with a surgeon.

The surgery improved Jim's quality of life. Dramatically. That was two years ago.

A new clinical trial. The spleen was massive. It was "uncomfortable," he'd say.

We were lucky with the clinical trials in that only one gave him side effects bad enough to make him quit.

None of them worked well after Jakify. Sometimes the blood work changed a bit, but not enough to make a difference. Though maybe cumulatively they did because he lasted 12 years and I know that six is a good number from onset.

In January of 2023 I told my best friend that, "this is the year." Jim was turning 80 in August.

I asked for 10 minutes alone with Dr. K. I wanted to ask the questions that Jim didn't want to hear. Jim left the room. Dr. K had no answers. I knew the statistics for what could happen. I just prayed that whatever took Jim it wouldn't be ascites. My brother died that way with lung cancer. His wife described it in terrible detail. "Anything but that," I prayed.

By May it was clear that I couldn't go for my yoga weekends. Leaving Friday, coming home Sunday, the escape let me change channels. By May it was clear that I shouldn't leave him

alone anymore. I asked him to wear his iWatch which was set to call me if he fell. I quit going to Sanibel and instead went to Bradenton. Never more than 45 minutes from home. But he was clearly weaker. The new magic drug wasn't doing anything, but it was better than nothing. Maybe.

Taking the drug(s) I think gave Jim the purpose that he was doing what he could. Our next-door-neighbor developed blood cancer. Dr. K was his physician, too. He died less than a year from diagnosis and before he could get a bone marrow transplant. Jim never found a match. The neighbor went to get his hernia fixed before the transplant and never left the hospital.

We quit going out to eat, but he kept eating and cooking, too. When his son came for his 80th I made it clear we would not be doing the usual dining out. Jim was still working with his 3D printers, creating, and constructing radio-controlled planes.

On a Sunday morning in September Jim asked me what it felt like when my appendix went crazy in 2020. He told me he thought he had appendicitis. He called the triage nurse at Moffitt who told him to report to the emergency room immediately. We packed up and departed.

Even then I didn't think it was his time. I just didn't feel it.

But it was horrible. Pain. Real pain. Failing kidneys. Failing liver. They put a catheter in, and it was horrible. More pain. Jim has a freakishly high tolerance for pain so when he's hurting others would be begging to be put out of their misery. The urine in his bag was black. I was horrified. But I wasn't afraid. It just wasn't his time. I sat with him all day every day. I asked the nurses not to wake him every hour. They respected that. There was a doctor with no inside voice. I had to walk him out of the room to talk. I got to hear everything about the poor bastard in the room next door. Jim was there and not. I was told that as his kidneys and liver fail failed "foggy" affect can be expected. Twice they drained the fluid around his spleen. While it was a relief, it came back with a vengeance the next day. After 10 days he looked at me and said, "Get me out of here." He was absolutely all there. I told the floor nurse. Hematology sent a young doc and an experience nurse, separately to talk to us about hospice.

"I just want to go home and be comfortable," he said parroting the exact words of the nurse. Standing in the hallway talking to her was the first time that I lost it. Not bad, but outside of Jim's room. I made it 12 years. Not too bad. It was September 8.

He continued to take the magic drug.

They liberated him the next day and thus began my tenuous relationship with hospice. The intake nurse, former military was great. The social worker was an incompetent, inconsiderate boob. The next nurse was OK. The visiting nurse wasn't staff, and she was

very good. They ordered a walker, which he hated. He'd pick it up and walk carrying it which I pointed out was just "showing off" for the nurses.

Jim deteriorated pretty fast. As time passed, Jim was losing clarity. He spent most days on the couch watching the plane-wreck channel. The retired pilot trying to figure out what went wrong before the NTSB did.

He son came back for a few days in early October.

Jim didn't want to talk about "stuff." That was his way. I had questions. I wanted to talk, but I was a supporting character in this part of his story. At one point I asked him, "Do you think this (hospice) was the right choice?"

"I do, do you?"

"Not my choice, Jim."

He had a problem with the 3D printer. It was acting like it was printing but it wasn't. He hadn't been physically in his office working with the printers since coming home from the hospital.

"Have you figured out air printing yet," I asked.

"I'm working on it," he said from the couch, eyes closed, head tilted back.

On October 12 Jim started vomiting blood. "Please God, not the ascites breaking." I called the nurse, and I called the cremation service. I signed a contract because I knew we were just about done. The good hospice nurse came on her regular Thursday visit. Jim was lucid, though he was in bed for the visit. That was a first. The nurse ordered a wheelchair and toilet because I had to help Jim up. She came back on Friday. It was stormy. The items were to be delivered on Saturday.

As promised, she came back Friday. Again, Jim was lucid. We left him in bed, and adjustable sleep number that raised feet and head, either or both. I hated that bed. I called it the hospital bed because that's what it felt like, but I was glad to have it for him.

We stepped into the kitchen to talk. Jim had been agitated so she ordered some Ativan from Publix. A friend picked it up and brought it to me. It helped him.

"What's next?" I asked.

"I declare him imminent," she said.

"What does that mean?"

"It means he will die in the next week. You'll have someone come every day. Sometimes a nurse, sometimes the social worker."

"He will die in the next week," I told her. "If that social worker steps into my house I cannot guarantee her safety."

She named the social worker, and I confirmed the identity.

"He will die this week," I told her.

“I’ll come back Monday,” she said, “You have the emergency number in case something happens?”

“I do.”

“Then I’ll see you Monday,” and she left.

Jim was spending most of his time sleeping.

Every time I heard the walker hit the floor I was up and moving. At 2 am Saturday the 14th I heard the walker and was out of bed to help him to the bathroom. He didn’t even know he was on the toilet.

I knew that we had turned a corner.

The next morning, I got up and put on my gardening clothes, but I didn’t go outside. For 35 years Jim was up before me. This much bedtime ... I knew ... and I knew I couldn’t be steps away.

At 1030 am, I was in the living room about 10 steps away and I heard the walker on the floor.

“Stop Jim. I’m coming.” But I got to him in time to watch him fall over. He was dead weight. I couldn’t lift him. I got a pillow for his head and called hospice. I got a nurse who told me to call 911.

“No. He’s 80 years old with cancer. I can’t risk someone saying he has to go to the hospital to get checked out. He has been clear for years that he wants to die at home.”

She gave me a non-emergency number to get some help. I called it but the call went nowhere. I called again. Nothing. No tone, not ring, no ding ding ding, “this number is not in service.” Nothing.

I called back. Different nurse. This one said that she isn’t handling Hillsborough County, that she’d get a message to the nurse I talked to earlier. I waited 10 minutes, checking on Jim intermittently. I called hospice and got voicemail.

I called a private nursing service. The woman told me that they don’t usually do intake on weekends but would pass the message to her boss. Within minutes the boss called back. I explained the situation and she said she would find someone, and we’d figure out the rest on Sunday.

The wheelchair was delivered.

In less than an hour a tall, dark, handsome nurse showed up and took over. He got Jim into the shower. He was bruised and bloody and out of it. Vacant beautiful blue eyes. Clear as ever but nothing behind them.

Four hours later hospice called. I let the woman on the phone know exactly what I thought of hospice. She apologized profusely but so what?

My Jim, an exceptional man, Air America pilot, brilliant and funny and resilient laid on the floor for nearly two hours.

The nurse took Jim to the back deck in the wheelchair. Jim's face was so smooth, tension from the past months vanished.

The nurse left at 630 to take care of another patient. He promised to come back around 830. I'd asked for 24-hour care.

I was mostly in my office. Jim was sleeping or slipping away. At 830 I went into the bedroom and whispered that I loved him. He was breathing.

Fifteen minutes later the nurse returned. At 9 pm he came to my office and said Jim was gone. He called hospice.

Uh oh. Now crying again.

So, this is a good time to tell you that I went to the back of the house, the bar, and made myself a coconut water with coconut vodka. I was standing in the kitchen collecting myself for the calls when the nurse joined me. He asked what I was drinking.

"Coconut fizzy. Want to try it?" He took a sip. "Want one?" I asked. He indicated yes. When I came back from the bar, he gave me a big, nursely hug. That was nice. We stood talking a little bit, then he offered to give me a massage and made it clear that if I needed a little something else, that was possible, too. I politely declined and went to make phone calls.

I may not have hormones, but maybe I still have pheromones? That's what I like to think, anyway.

I asked him to dress Jim in a fishing shirt, the blue one, and jeans, his daily uniform. By 1 am everyone was gone.

I was alone.

What to tell patients about clinical trial drugs.

- Much of what you experience will be due to attitude and fortitude.
- You must give it time to work, or not.
- Maybe you'll get a magic bullet, but mostly improvement will be incremental. It's all good.

- There are things that we don't know, like how sequential clinical trials might benefit you.
- You are not alone. Find friends. Create community. Connect.
- Keep living your life and doing the things you love for as long as you can.