



Alec Hill

LIVING  
IN

*Surviving Cancer, Finding New Purpose*

BONUS  
TIME



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# 1

## MY STORY

*Chemotherapy is brutal. The goal is pretty much to  
kill everything in your body without killing you.*

**RASHIDA JONES**

*An individual doesn't get cancer. A family does.*

**TERRY TEMPEST WILLIAMS**

*Cancer is a wake-up call to remind us how high  
the cosmic stakes really are . . . and how  
short, brief, and frail life really is.*

**JONI EARECKSON TADA**

*Cancer is a disease of the genome. Mistakes in a cell somewhere in  
your body cause it to start to grow when it should've stopped.*

**FRANCIS COLLINS**

**E**IGHT YEARS AGO, my doctor prescribed a variety of creams to reduce what appeared to be a common fungus familiar to most men—jock itch. Each product seemed to work for a while, but the rash continued to slowly spread. This went on for nearly a year. Finally, as my wife, Mary, and I prepared for a long trip, I asked to see a specialist.

Imagine my surprise when the dermatologist wanted to take a biopsy. “Down there?” I naively asked. After the procedure was conducted, I limped home.

A week later, while on a work-related trip, I listened to a message on my phone. “Mr. Hill,” the dermatologist said in a flat voice: “You have an extremely rare type of glandular cancer. We haven’t seen a case of Male Extramammary Paget’s Disease (MEPD) in more than a decade.” As I literally fell to the pavement, I recall him saying something about “removal.”

Was this really happening? Sitting on the ground, I googled MEPD and read a scientific paper about the horrors experienced by men in Africa. Another article stated that my cancer was extremely rare with only five hundred cases reported worldwide annually. My reaction? Fear. Didn’t glandular imply that the cancer would travel on my body’s interstate highway? Might I lose a testicle . . . or worse? Could it spread to my brain? Might I die?

A few days later, I found myself as the primary subject of the “grand rounds” of the University of Wisconsin dermatology department. I understood this to mean that thirty doctors would examine me, trying to diagnose my rash and provide advice regarding next steps. Since a second opinion was needed, I reasoned, why not a whole team?

## MY STORY

Who would have guessed that nearly half the observers would be female interns about my daughters' ages? As their little flashlights illuminated my private parts, any sense of modesty dissolved. I now better understand something of the indignity that women must feel during pelvic exams.

Not one of the specialists guessed my ailment. How could they? None had ever seen MEPD before. A tear glided down my cheek when I heard the consensus that I would not lose any body parts. I quietly thanked the Lord and held Mary's hand. What an incredible relief. But bladder, rectal, and colon cancer were still very much in play.

Through a providential connection at the Mayo Clinic in Minnesota, an appointment was made with a leading dermatological surgeon. There remained a very real risk that the cancer had spread to other parts of my body. For about a week, I struggled with the possibility of dying. Having only briefly brushed up against mortality in the past, I was totally unprepared for the emotions that poured out. It felt overwhelming.

After a scan showed no signs of the cancer spreading, I nearly jumped up and hugged the doctor. Even better, no radiation or chemo would be required. Still, the surgery lasted seven hours and required more than fifty stitches. That night I awoke in a hotel room, feeling something hot on my leg. The next day, the doctor seriously mulled the possibility of resewing the wound. I was horrified by the prospect. Thankfully, after hosting a lengthy consultation with a colleague (and waiting for the bleeding to stop), he decided it was unnecessary.

Three weeks in bed at home followed. At first, standing up and walking were difficult. I hurt. In particular, going to the bathroom

was challenging. Eventually, I went back to the office, thankful that my altered private parts were not visible to the outside world. Within two months, strength returned and I was able to resume my precancer life. Little did I realize that this was but a prelude to the main event.

### FAINTING SPELL?

**Diagnosis.** Fast-forward four years. As I bent down to grab yogurt out of the refrigerator, I blacked out and fell to the floor. Never having fainted before, I chalked it up to exhaustion after an eight-day trip on which I gave six talks in three cities.

Minimizing the incident, I made a conscious decision not to tell Mary. Why worry her? Of course, masked in this language of “marital care” was my fear of being grounded. My upcoming schedule, I rationalized, was simply too packed with important stuff to be interrupted.

A few days later, I shared what happened with my pastor and added that I had inexplicably lost seven pounds over the past few months. Looking at me with incredulity, Chris gave two pieces of advice I’ll never forget: “First, always tell your spouse. And, second, never self-diagnose.” He also let me know that if I didn’t tell Mary, he would.

After appropriate groveling, I confessed to Mary. My penance was to see my general practitioner ASAP. He was unavailable, so an on-call physician examined me. Reviewing results from my blood test, she concluded, “You need to see an oncologist now.” When she learned that there would be a seven-week delay in my appointment, she bypassed normal procedures and called the specialist’s office herself to insist that I be prioritized. In doing so, this substitute doctor—whom I only met once—probably saved my life.

While describing my symptoms to the oncologist at the University of Wisconsin, I witnessed his mind clicking—weight loss, anemia, lightheadedness, decreasing energy, flu-like signs but no temperature. It was late Friday afternoon. Normally, he would have scheduled a bone marrow biopsy the next week with a nurse who specialized in the procedure. But, because he wanted the lab results immediately, he decided not to wait. Apologizing in advance for his heavy hands, he inserted a long needle into my hip, broke off a small piece of bone, and extracted it. Needless to say, it was a long ten minutes. His nurse held me down while I writhed in pain.

As we prepared to leave the office, the nurse gave me clear instructions to go to the hospital if I got sick over the weekend. When asked if her concern was related to possible infection from the procedure, she said no. She was worried about a compromised immune system.

The follow-up appointment was a shocker. The oncologist stated, “Mr. Hill, I have bad news. You have a cancer known as Myelodysplasia Syndrome (MDS). Your bone marrow is producing mutant white cells. If untreated, your immune system will fail, and you will die of a common cold within eighteen months. Its symptoms are similar to AIDS.”

Swallowing hard, I asked, “Is it as bad as leukemia?” His response jolted me: “It’s worse. There’s only one possible cure—a bone marrow transplant. Of ten MDS patients, five will survive (defined as living two years, not exactly reassuring). Of those who live, three will have serious physical limitations. Only two will resume relatively normal lives.” I later learned that notable MDS patients include TV anchor Robin Roberts (a survivor), astronomer Carl Sagan, and author Susan Sontag.

I imagined Mary living as a widow. I cringed at the prospect of informing our daughters, Laura and Carolyn, of yet another cancer. Death felt very close.

**Second opinion.** The next week Mary and I flew to Seattle for a second opinion. Half a century ago, bone-marrow transplants were pioneered at the Fred Hutchinson Research Center, so we knew we were in good hands.

Flying west, I journaled: “I’ve lived an incredible life. I wouldn’t trade it for anyone else’s. So, if the ride ends in the next eighteen months, I take great solace. I’ve loved deeply and been deeply loved.” Despite the grim circumstances, I richly felt God’s presence.

Entering the Seattle Cancer Care Alliance (SCCA) for the first time, my body involuntarily constricted at the smell of strange chemicals. David Scadden, professor of medicine at Harvard, aptly labels this foreign environment *Cancerland*. Questions popped into my mind: *Why are so many patients sitting alone? Will I become ashen like them? Why is it so quiet?* Scadden observes:

A cancer diagnosis sends you into an alternative reality, Cancerland, where the usual things in life recede and it’s easy to be overwhelmed by your condition, your treatment, and your prognosis. In Cancerland, you learn a whole new language . . . and you scan the horizon for signs of hope or danger.<sup>1</sup>

Following a round of lab work, my new oncologist placed me in a high-risk category. Of the ten thousand people who contract MDS annually, only five hundred have damaged third chromosomes. Extremely rare, *chrom-3* is regarded as chemo-resistant—horrible news since chemotherapy is central to the treatment.



My mind raced. Only five hundred people in the world? Can this really be happening again? Can lightning strike twice in the same place? Why me?

Since my cancer was so rare, SCCA doctors—despite being overbooked—opened a slot for me. Chrom-3 was both my curse and my ticket. Within three weeks, I resigned my position with InterVarsity, Mary prepped and sold our Madison condo, and we moved to Seattle. Every day, we were acutely aware of the monster lurking around the corner.

***Transplant.*** The first order of business was to test my two brothers, Cy and Grant, to see if either was a bone-marrow donor match. The odds of a sibling match were 25 percent. If that failed, my oncologist would move to Plan B—the international donor pool. But the wait could take several months. Our daughters were by default only 50 percent matches.

Imagine our joy when Grant was identified as a perfect match. This also meant that my treatment would be expedited. Unlike MDS patients who rely on the international pool, I only had to endure a single month of pre-chemo shots to my stomach. When the nurse entered fully masked and gloved, I grasped the high toxicity of the chemicals being injected. Over the next few days a burning red circle of inflammation tormented my flesh.

Mary and I moved into an SCCA apartment, our home for four months. It was an odd environment where seventy transplant patients and their caregivers were told not to interact with each other. To prevent germs from spreading, there was no air-conditioning system. Though midsummer, we were instructed not to open our windows—it was critical to keep urban contaminants such as dust and mold out of the building. Sanitizer dispensers were hung on every floor.

For five days—after having a chest catheter surgically implanted—I received massive doses of chemo to kill all my white cells. On the day of full body radiation, with gallows humor, I chuckled when the radiologist said that I wouldn't be having any more children. At my age and stage, this comment was rather comical. But it also struck me that for women and men of child-bearing age, such news would be incredibly tragic. Blocking the estrogen that feeds their cancers or reducing the sperm count obstructs their ability to conceive children.

Grant's timeline and mine were handled independently but needed to merge on "day zero." As my blood counts plunged, he was being prepped by a separate medical team—a safeguard to avoid risking his health for my benefit. His goal was to produce five million stem cells. After receiving several shots, less than one million were harvested. The process was repeated a second day with the same results, providing only a total 1.7 million (37 percent of what was needed). Grant's platelet level dropped so low (from 195 to 40) that he needed a transfusion and could not give additional stem cells for several days. At age sixty-four, too much may have been asked of his body. Bone-marrow donors are typically young adults.

Thankfully, Grant's team had an ace up its sleeve—a \$16,000 megashot. Feeling his body rumble, he didn't sleep much. The next day, he produced 2.2 million more units, bringing the total to four million. While less than optimal, my doctor said that it would have to suffice. The only other option was to shut down the transplant process and seek another donor from the international list. The risk of my decline in the ensuing months was simply too great to delay. Due to my treatments, I now had no functioning immune system.

## MY STORY

Grant is a physical marvel—six feet four inches tall, 175 pounds. Prior to my transplant, he had biked across Iowa. But the procedure really beat him up, leaving him exhausted. Afterwards, his team counseled him to avoid any activity that might cause internal bleeding. His blood lacked the ability to coagulate properly. For the next six months, his white cell counts remained abnormally low.

The transplant itself was rather anticlimactic—more like a transfusion really. For four hours, Grant’s stem cells dripped into my chest catheter. Fully conscious, I mostly read magazines.

For the next twenty-three days, while waiting for the transplant to graft, my white cell count was zero. Taking fifty pills a day, I became very ill. Scabs peeled off my radiation-fried body. Twenty pounds lost. Blood transfusions. Yellowish translucent skin. Incessant diarrhea. Insomnia due to steroids. It was truly a Job-like experience.

To minimize the risk of infection, Mary constantly sanitized every square inch of our apartment. Everything—bedding, towels, and clothes—had to be washed three times a day. She bathed me, changed the dressing on my chest catheter, monitored my medications, and cooked special meals. She was a saint. In virtual lockdown, we saw neither family nor friends.

As many cancer patients know, one of the side effects of receiving massive doses of poison is *chemo brain*. I couldn’t read or complete sentences. All I could do was sit in a recliner, work on simple crossword puzzles, and watch TV.

For eighty-seven consecutive days, I was hooked up to receive infusions for up to four hours. While not painful, it was very awkward to use the bathroom. Tethered to a pole, I walked the

clunky apparatus down hallways, always being careful not to tangle wires and tubes (one of which was screwed into my catheter).

I wondered, *Is this hell?*

## REFLECTION QUESTIONS

1. Describe a situation when you—or someone you love—was given horrific news. What phases did you go through emotionally? What questions did you ask God?
2. Reflect on Psalm 88. What does it say to you?

LORD, you are the God who saves me;  
day and night I cry out to you.

May my prayer come before you;  
turn your ear to my cry.

I am overwhelmed with troubles  
and my life draws near to death.

I am counted among those who go down to the pit;  
I am like one without strength.

I am set apart with the dead,  
like the slain who lie in the grave,  
whom you remember no more,  
who are cut off from your care.

You have put me in the lowest pit,  
in the darkest depths.

Your wrath lies heavily on me;  
you have overwhelmed me with all your waves.

You have taken from me my closest friends  
and have made me repulsive to them.

## MY STORY

I am confined and cannot escape;  
    my eyes are dim with grief.  
I call to you, LORD, every day;  
    I spread out my hands to you.  
Do you show your wonders to the dead?  
    Do their spirits rise up and praise you?  
Is your love declared in the grave,  
    your faithfulness in Destruction?  
Are your wonders known in the place of darkness,  
    or your righteous deeds in the land of oblivion?  
But I cry to you for help, LORD;  
    in the morning my prayer comes before you.  
Why, LORD, do you reject me  
    and hide your face from me?  
From my youth I have suffered and been close to  
    death;  
    I have borne your terrors and am in despair.  
Your wrath has swept over me;  
    your terrors have destroyed me.  
All day long they surround me like a flood;  
    they have completely engulfed me.  
You have taken from me friend and neighbor—  
    darkness is my closest friend.

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