

## The gift of hope

Love of family and friends eases painful transplant battle

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Carlyn Cygan is writing in her journal, waiting for her fiance Scott Michelson to get his second cancer radiation treatment.

The 26-year-old sits in the basement of Seattle's Fred Hutchinson Cancer Research Center. The light is dim. Industrial. A motor churns nearby from a pop machine.

As she writes, her brown hair sweeps forward. Her eyes are red-rimmed.

She's frightened. She's trying to be courageous for Scott, who was diagnosed eight months ago with chronic myelogenous leukemia. But she's never experienced anything like this.

A tear pops onto today's lined page in her journal, smearing the ink slightly: May-13-1996, 2:15 p.m.

*First day of radiation. Today is not a good day. Scott has thrown up six times already. ... He said the radiation wasn't painful this morning at all but he is very sad. ... He's throwing up blood, mucus and bile. ... They're giving him an IV hydration which is good. ... Scott is so brave.... "*

In just three days, Scott, 27, will get a bone marrow transplant, his only chance to live.

The leukemia in Scott's body is causing his bone marrow to produce thousands of immature white blood cells, which are crowding out other blood cells.

The only cure is to have healthy bone marrow injected into his blood stream and enter his bones. If all goes well, the new marrow will start making blood.

But the transplant could also kill him. To prepare for it, his own cancerous marrow must be destroyed. If his



In July 1996, as Scott Michelson was recovering in suburban Seattle, his fiancée, Carlyn Cygan, visited every weekend.

body rejects the new marrow, Scott will have no immunity against infection and no way to make healthy blood any more.

In the first room of the radiation therapy area is a video screen, microphones, speakers and a wall of control boards. Here is where the radiation techs and nurses sit, safely shielded from the invisible streams of alpha particles, electrons and gamma rays emanating from inside the second room.

Scott is in the second room.

He's stretched out on a hospital bed, wiggling just enough to place his body directly beneath a pulsating red light. The light, shaped like a cross, is a guide showing him where he needs to position himself.

Mounted on the ceiling of this windowless room are video cameras; a tiny silver microphone dangles above Scott's head from a black cord - high-tech eyes and ears for the medical staff in the first room.

Scott hears silence. No whoosh of ventilation. No hum of fluorescent lights. The lead-lined walls of the room blot all noise.

Two radiation machines, 7 feet tall, stand on either side of his bed. The machines look like propane tanks. Tracks are built into the floor so the therapist can easily move the machines to regulate the radiation dosage.

Green lights on the machines sud-

denly switch dark. Two lights glow red.

"Uh, am I getting cooked now?" he asks.

"Yes, Scott, we're zapping those bad cells," says the radiation tech. Her voice sounds small transmitted from a tiny speaker. "You won't feel any pain. Just try to stay still and relax. It's OK to watch television, too, if you like."

His thumb pushes the "on" button and the television pops with a bluish glow. Oprah Winfrey's face fills the screen. He sighs. He's not in the mood.

He flicks off the television. Closes his eyes.

His first day of radiation is almost over.

### Around 6 p.m., May 16, 1996

Word spreads fast on Scott's hospital floor that the courier from New England, a nurse, has arrived. She carries a cooler filled with bags of bone marrow, straight from the hip of a stranger.

Nurses crowd into Scott's room. Scott and Carlyn's families are here, too. Carlyn holds Scott's hand.

In one corner, bobbing up and down, are 10 balloons - a gift from Carlyn's parents. Wrapped presents wait on another table. Scott is about to get his second chance at life, his second birth.

Someone starts singing, quickly

joined by a robust chorus: *Happy Birthday to You, Happy Birthday to You ...*

A birthday celebration on the day of the marrow transplant is a tradition at the Hutchinson center, also known as The Hutch. Every day before the transplant is a countdown, until "ground zero," when the patient's blood counts are literally near zero.

"The guy who gave you this is really hurting," says a nurse as she hangs the first bag of marrow to an IV pole. The marrow looks like lumpy ketchup in a clear bag. Because of Scott's size – 240 pounds – he must get five half-liter bags.

Weeks earlier, surgeons placed a Hickman catheter directly into Scott's chest. The Hickman catheter has two plastic prongs sticking out. The prongs are an easy way to give medications, chemotherapy, liquid food supplements and new bone marrow. The transplant is as simple as connecting a plastic tube to one of the prongs.

The clear plastic tube connected to Scott's catheter becomes a line of red.

"This stuff really knows what to do?" Scott asks a nurse. "This is it?"

Every leukemia patient asks this question, says Christy Satterlee, who counsels patients and their families on the transplant floor at The Hutch. She answers the question the same way every time: "It's like presto-magico, the marrow goes right to the spot it's needed. Science still hasn't figured how the marrow works exactly. We just know it works."

As the first hour passes, Carlyn wonders about the donor.

"Can you tell us anything about him?" she asks the courier.

"He's a semi-pro golfer who lives in New England," she says. "And he's the father of two girls, too. That's all I can tell you."

"Hey, maybe his marrow will help my golf game," Scott jokes.

Some 2,400 miles away in Farmington, Conn., Bob Booth, 49, is waking up from the marrow harvest.

Doctors extracted Booth's marrow from his hip with 100 pulls of a syringe. They needed a lot of marrow.

Booth is a little sore. A little tired. And very elated that he might have helped a stranger with leukemia. Tonight, he'll say a prayer for him. Tomorrow, he'll go home.

God bless him, Carlyn writes in her journal. If only he knew how many

lives he has affected.

The hospital's night shift arrives. Scott's nurses and family members say their goodbyes. The hallways grow quiet. Carlyn writes some more:

*Oh, what a day. I feel kind of numb. I wish I had some good words to say to the courier. She was going to reply to the donor. All I could think of was "Thank You!" ... It's amazing that right now new life is being pumped into Scott. God, I hope it takes.*

*I love him so much. ...*

As the thick marrow drips into Scott's body, he sleeps.

After a few hours, he even snores.

## May 23, 1996

One week after getting the marrow, the side effects begin.

Scott's hair, what little is left, falls out. Before he was admitted to the hospital, he and Carlyn had a shaving party. She gave him a buzz cut. Now he doesn't even have eyebrows.

His stomach stays upset, along with waves of hiccups lasting for two days and nights, even while he sleeps. Then early one morning, he wakes to bloody sheets, blood on his pillow, blood on his face.

It's a nose bleed. And it doesn't stop.

At 2 a.m. his nurses summon the on-call doctor. A blood transfusion of platelets is ordered for Scott. Scott can't talk. His tongue is swollen. He's miserable. He has a full-blown case of the side-effect he was dreading most – mucositis.

Mucositis is when the fast growing cells in the gastrointestinal tract slough off, leaving skin raw. Sores pop up in the mouth, throat, lips and tongue. Scott can't even lick an ice chip; it hurts too much.

Carlyn squeezes water from a cold washcloth and dabs Scott's face. As platelets drip into his Hickman catheter, she puts soft jazz on the portable CD player. She massages his feet, then rubs his forehead. After four hours, his nosebleed stops.

Carlyn watches Scott sleep, wishing that he could sleep for a week and wake up free of the mucositis. Pain medication helps him only a little.

His feet twitch. Carlyn buzzes a nurse to report it. The nurse assures her it's OK. We'll just name him "dancin' feet," the nurse says.

Dancin' feet, Carlyn thinks, then smiles – the first time she's really smiled in a while.

One morning Scott looks in the

mirror. His skin is the color of milk. He is shiny bald. His body seems translucent, with purple veins zigzagging like an interstate road map. He curses at the sight.

The nurses track how he feels. How much nausea he has. How much he eats. He drifts in and out of pain medicine-induced drowsiness. Every day there is a blood draw and the continuous hope that his blood counts will rise. They watch Scott closely for symptoms that the new marrow isn't working. A good day now is when he can just sit up.

Carlyn tries to cheer him by pasting up his get-well cards on the wall in front of his bed. Scott has more than 90 cards and letters.

Twelve days after his transplant, Scott's condition still hasn't improved. This is his most dangerous time. Before the new marrow kicks in, he doesn't have enough healthy white blood cells to fight off an infection. Even a cold could kill him. Visitors must first sign a release stating they don't have as much as a sniffly nose.

Lingering always is the threat of death. Late one night, noises in the hallway wake Carlyn. She learns a patient has died, and knows which family's vigil is over. She slips out of Scott's room to cry.

On the 14th day after the transplant, nurses tell Carlyn and her mother, Andrea Cygan, to start attending the home after-care classes.

"As bad as it looks now," says one nurse, "Scott will probably be going home in another 10 days. He is progressing normally for a bone marrow patient. And actually, he's doing pretty well."

Carlyn is elated. She writes again in her journal, this time in hand writing that grows into fat loops and curlicued swirls: *We needed this. ... Both of us.*

## June 5

Twenty days after his transplant, 30 days since he was admitted into The Hutch, Scott is given a pass to walk outside for a few minutes.

First, he slathers on sunscreen. The drugs and radiation have made him susceptible to sunburns and skin cancer. Then he walks through the hospital doors.

Beneath the trees in the front courtyard are several slatted park benches. Carlyn walks with him, holding his

hand. Scott walks slowly to one bench, lowers his body on the seat and takes a deep breath.

He looks up and sees the cobalt-blue sky. White-peaked mountains rise in the distance, beyond the angled buildings and windows of glass. Downtown traffic lurches past, with sleek Lycra figures on bicycles darting around construction snarls.

Scott smiles.

"I forgot how good it is to be outdoors," he tells Carlyn. And then, he can't help himself, he cries.

And so does she.

Six days later, Scott is discharged from the hospital and begins the outpatient treatment. He moves into the suburban Seattle home of his future in-laws, Andrea and Tom Cygan.

Just 15 minutes after he arrives, he throws up.

He will live here for the next three months. His future mother-in-law volunteered to care for him. The Cygans' home is minutes from the hospital.

Carlyn flies back to Kansas City. She's taken six weeks off from her job as a sales trainer at Hallmark Cards Inc. Her routine now: cramming 40 hours of work into four days so that every Thursday night she can fly back to Seattle, and to Scott.

Scott's medical routine is still a 24-hour regimen. Every night, Andrea Cygan sleeps on a comforter on the floor by Scott's room. She doesn't know when the alarm will sound signaling that his nutrition bag is empty. Until Scott can eat, this is his only source of nutrition. Andrea doesn't want even a half hour to pass without Scott eating. She also wants him to rest.

She sets other alarms throughout the day, monitoring the dozens of pills he needs against infections and pain. She makes a chart, marking off what he's taken and what he still needs. She cooks bland food when he can eat.

Every day, Andrea drives to the hospital for his supplies. She also drives him back and forth to doctor's appointments, blood tests, infusion therapies, physical therapies and marrow tests.

In September, one year after his initial diagnosis, Scott flies home to Kansas City.

## Back home

Scott is self-conscious about his appearance. His face is puffy. He worries he looks fat. He's still bald, with just a whisper of fuzz. And he's frail.

To Carlyn, none of that matters. They can finally start living again.

The couple plan their dream wedding. They also start looking for a house.

In May 1997, Scott and Carlyn return to The Hutch in Seattle for his one-year checkup. The couple will be married in weeks.

After his bone marrow biopsy, the nurse returns with tears in her eyes: Scott's biopsy shows signs of a relapse.

"No! No! It's not happening. Tell me it's not happening!" Carlyn cries. Several nurses at The Hutch duck into an empty room when they hear. They cry, too. Scott is one of their favorite patients.

"I'd rather be married to him for two years and be a widow than never ever marry him," Carlyn says to a Kansas City friend in a late-night phone call. "We're devastated. Please don't tell anyone. We're still going to be married."

The doctors try one desperate measure. They take Scott off all his other medications and give him just one, a drug called interferon. Doctors hope it may jolt his marrow into making healthy blood. But the drug has several side effects, including flulike symptoms.

Scott and Carlyn keep planning their wedding. Too many times they've had to cancel their lives for this disease.

On a sunny afternoon on June 21 – Scott's deceased mother's birthday – Carlyn and Scott are married at Holy Cross Catholic Church in Overland Park. As the music soars and flower girls throw petals, Tom Cygan walks his daughter down the aisle. Carlyn's face glows.

Many of the more than 300 friends and family who witness the ceremony are unaware of Scott's relapse. But everyone knows the couple's history and what they went through.

In the ceremony, as Carlyn tells Scott "in sickness and in health," her voice cracks with emotion. Scott wipes her tears away.

July 19, Scott has another doctor's appointment in Kansas City. His blood counts are monitored regularly now.

Scott doesn't remember driving to their new home after the appointment. He only remembers that the traffic was moving too slowly, traffic lights all turning red.

Finally, he arrives and sees her, his new wife, his best friend. She is standing in what will soon be the front door to their new house in Olathe. Carlyn and some friends are inspecting the construction.

She hears his car, stares, as Scott lurches to a stop, tires squealing.

"Twenty out of 21!" he yells to her, running up the driveway. "Twenty out of 21!"

No one else around them understands this secret code.

No one understands, except Carlyn. The test showed that 20 out of 21 cancer cell markers are free of leukemia.

Carlyn sinks to her knees in joy. He picks up his new wife, holds her in his arms.

Carlyn laughs, then cries, then laughs some more.

Scott is not cured. Nor can he say he's in permanent remission, not until five years pass with his good health. But tests show that the marrow is working normally.

Today, the Michelsons got their lives back.

"All we need now are some little Michelsons," Scott says with a grin.

Trying to conceive a child won't be easy, however. As it stomped through the Michelsons' lives, leukemia left one of its ugliest footprints: Scott is sterile.

But inside a laboratory at the University of Kansas Medical Center are 10 vials of Scott's sperm, cryogenically frozen since 1995.

Medical science saved one Michelson life.

Maybe medical science can help create another.