Transplant: a non-fiction narrative

M Rowe

This narrative is taken from a memoir about my son, Jesse, who died at age 19 in 1995 after a liver transplant. It covers two periods—from May 5, his admission date at the hospital to wait for a transplant, until May 9, when a perforation, caused by cutting through intestinal adhesions during transplant surgery, was discovered, and from May 20 to May 22, when his condition became extremely critical. Since Jesse was largely unconscious or semi-conscious during a good part of the period this narrative covers, his personality and conscious struggles shine through less here than they do in other parts of the memoir. Here, the relative emphasis is on parents and physicians and on facing the critical illness, and possible death, of one’s child in an intensive care unit, following the very intervention that was to give him a new chance at a healthy life.
He mimicked, by the shake of his head and its inclination toward the wooden table in front of him, his amazement at Jesse's liver when he opened him up and, fingers extended toward the wooden table, the feel of Jesse's liver through his gloved hands.

His liver looked so good. A little firm, but not what we expected. We were puzzled.

What made you decide to go ahead?

His overall condition. We couldn't see any other reason for his symptoms. The fatigue, the portal hypertension, the spleen.

Did he get much blood?

He might have had a unit or two, I don't recall.

I had the impression he could have recalled quite well. His answer was a form of reassurance. The less blood given, the more routine the surgery. We were surprised to hear about the condition of Jesse's liver, even more surprised to hear Dr Dorand talk so openly about their indecision. It was possible that Jesse hadn't needed a new liver and the lifetime of drugs that went with it to hold his immune system at bay once it detected the intruder. Perhaps honesty was simply Dr Dorand's style. He may have trodden on slippery ground when he met us at the clinic a couple of months before and he told us, in so many words, that he would treat Jesse ahead of a sick old man sitting at home watching TV with a beer belly from fluid leaking out of his blood vessels. But why be so forthright when it might come back to haunt him? The question answered itself in the asking, of course. It wouldn't come back to haunt him. Here was an individual, good with his hands, who could appreciate the dovetail fit of absolute candour and legal strategy. He had been forthright with us about a judgment made on the spot with a year and a half's worth of blood tests and x rays and clinical visits to back him up. If calamity struck we would be devastated, but he had been honest about his doubts in a difficult situation that allowed for no easy answers.

We asked him about the donor. He hesitated. A twenty-year-old male from Manhattan who died from a gunshot wound to the head.

The best organs, we learned, come from healthy people who die violent deaths, not those who die in the hospital loaded up with drugs that have made their way through the organs to be harvested.

Infection will be our biggest problem. We can deal with rejection. Hopefully, this will work for him.

He got up to leave, and took our hands.

I'm happy. I hope you are too.

We were happy. Now we had to wait during the rest of the surgery to hook up the bile ducts of his new liver to his intestine and close him up. We could see the night sky through the glass rafters overhead when Dr Boyd, the assisting surgeon, came in. He was six-foot-six and trim but powerfully built. He rocked back and forth on his heels and tipped his head back when he talked or listened. I wondered if the faraway look in his eyes was a sign of fatigue or of compensation for having to think more clearly, though. Maybe the pain had driven away a fog of anaesthesia.

Walking back to the unit the next morning after a coffee run, we met Joan taking a break in the lounge. Her eleven-year-old daughter, Laura, had cancer. Her Broviac, a piece of hardware that delivered medication to a shunt surgically installed in her abdomen, had malfunctioned. They had to remove the Broviac and replace it, then watch her closely on the intensive care unit (ICU). Joan's husband wouldn't be here for hours and she wouldn't leave the unit. We went out and bought her an espresso and a croissant. She tried to pay us. I was glad to make contact with someone outside of medical staff and family, but I grieved for them. Even Jesse's troubles seemed small compared to those of a child who had to carry around a box to pump medication into her that made her hair fall out.

Jesse was waking up, slowly. They took the breathing tube out of his mouth. He was getting a powerful drug called Fentanyl for pain, and IV albumin, a protein, to help him pee. They catheterised him. He had drainage tubes near his Mercedes incision, a large inverted Y cut into his abdomen, a happy conjunction, for the surgeon who named it after the automobile logo, an image of luxury superimposed on an image of pain, an evocation of status equal to the status of liver transplants over Volkswagen kidney, Saab heart, and Lexus heart-lung transplants. Jesse's nurse, Tina, covered his incision, stapled shut and surprisingly tight and clean, with fresh layers of gauze every few hours.

He slept a good part of the day. By evening he was wide awake, though. We congratulated him. He was not yet ready to celebrate. At times he seemed confused.

So what are we going to do tonight, Mom?

He thought this was a Saturday night in Norwalk.

I pulled out his catheter on the night shift. The next morning he was still confused. His bedroom in Norwalk was across the hall. He sat up and tried to get out of bed.

I have more lines in me than I did last night.

No Jesse, it's the same number of lines.

No, there are more.

He told Rachel that Angela, who had worked the night shift, was a killer nurse. She was the one who added the other lines, he said. The chief resident tried to convince him that it wasn't so. Jesse shook his head with the confidence of one who knows what he knows and sees no point in further argument. He was still in pain. They gave him more fentanyl. He was thinking more clearly, though. Maybe the pain had driven away a fog of anaesthesia.
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Can I get something to drink? I'm thirsty.

Let me ask Dr Meyer. Jesse, Dr Meyer, the ICU attending, came in and asked him how he was feeling and whether he had any gas or stomach pains. No, he was feeling all right. She said he could have some apple juice. He drank it greedily. Around noon an aide came in and left a full lunch on the portable table near his bed. I was surprised. He must be doing really well.

Can I have some milk, Dad?

I went to get it for him, then stopped. Milk is so thick. True, he'd had juice earlier, and there was the tray just out of arm's reach.

Hold on for a minute, Jess.

I went out to the nurse's station. The nurse said he could only have clear liquids. They had ordered a parent tray for us.

Early that afternoon he complained of a sore back. I gave him a massage and thought about how little we touched and how I would find excuses, goofing with him. Once when he was fourteen I came home from work and walked into the living room. He was sitting on the couch with Daniel. I opened my arms in mock astonishment as though the two of them were long lost children I'd had no hope of seeing for years to come. He jumped up in mock astonishment of his own, cried Dad! and threw his arms around me. I was happy, and happy for him.

How does that feel?

Good.

Is that where it's sore?

Yes, and a little lower down.

His back felt warm. He had been lying on it for a while. He was so thin. His skin was so youthful, soft here compared to his poor scarred belly. I felt both sympathy and elation. I'd heard that a chronic sore back was one of the drawbacks of a liver transplant. So he was on the right trajectory, and so soon! That afternoon he sat in an easy chair. Dr Dorand came by on rounds.

How are you feeling, Jesse?

Pretty good.

Are you in any pain?

Not too much. Some.

Have you had anything to drink?

I had some apple juice.

Dr Dorand turned to us and smiled.

He doesn't really need to be here now, but the nurses like to keep them for a few days.

Gail was going home to be with the children. She didn't think Jesse was doing as well as his doctors did. She kept notes on his heart rate, blood pressure, pulse, and oxygen saturation rate ("SATs"), which shows how well the lungs are moving oxygen through the blood. His heart rate, pulse, and blood pressure were going up and his SATs were down a bit. He was getting a lot of fentanyl. His haemoglobin and haematocrit (red cell volume) were down. He had a slight fever. She showed the numbers to the nurses and the resident. They weren't concerned. I looked at the numbers and worried with him, but not without balloons, a cake, and a large gathering of doctors and nurses. Tina is here. Winks are exchanged around the room. The two of them write and call each other and we come by the paediatric intensive care unit (PICU) after his appointments at the liver clinic. One day he makes a phone call to his mother and then has something to tell us. We are happy for both of them, grateful to Tina for taking care of Jesse and, through a happy accident of timing and crisis, helping him through the treacherous passage from adolescence to manhood. We are proud to have her for a daughter-in-law . . .

The next morning he had pain in his belly and needed a lot of fentanyl to take the edge off. He vomited and belched. Drainage the colour of coffee grounds leaked into the tubes near his incision. A technician who looked a bit like Charles Laughton in the Hunchback of Notre Dame wheeled in a portable x ray machine. The x rays showed what might be an ileus, where the intestinal wall stops making contractions to digest food. An ileus can come from a kink in the intestine or from an infection. They're not uncommon after intestinal surgery, but they had to watch to make sure that what looked like an ileus wasn't an obstruction, where the intestine above the part that's blocked keeps working like a fire hose when the water hits a tight kink and pressure builds until the hose springs a leak or, in this case, bores a hole in the intestinal wall and starts dumping its contents into the abdominal cavity. This can lead to peritonitis, an inflammation of the lining of the abdominal cavity, and that can lead to sepsis.

But Jesse's belly was soft, not tender, a good sign. At eight-thirty in the evening they gave him the first of a triple dose of three powerful antibiotics. Rachel and Will left to take their turn at the transplant shelter. I was still trying to decide whether to go back to New Haven three days later for a presentation with my boss at the Yale School of Medicine on the homeless outreach programme I have running for the Department of Psychiatry. I could take the train in Friday morning and come back in the afternoon, but I'd be happy for an excuse to pass.

The pain got worse.

Where does it hurt, Jess?

Here.

He made a circling motion on the left side of his abdomen. He was writhing on the bed, rolling from side to side on his back. It hurts! Can't they give me something?

OK Jesse, hang on, they're trying to figure out what's going on . . .

Carol the resident was holding off on pain medications until someone from the liver team could evaluate him. She was fact, has told us she's having problems with her boyfriend who's away on business too often and doesn't spend enough time with her when he is in town. Marriage? They've been going together long enough for the subject to come up, but he avoids it.) Tina isn't that much older than Jesse. She's getting to know his inner silence and wariness and he doesn't scare her off. Her big sister interest in him ripens into a touch of something else. Something ripens in Jesse too. He goes upstairs. She visits him, taking report from us and giving report on her shallow inattentive boyfriend.

Jesse is doing well on the floor but his is a special case. Before his transplant he had portal hypertension, high pressure in the portal vein that carries blood from the intestine to the liver. It disappeared when they put in his new liver, but it had been abnormally high, especially considering the relatively benign condition of his own liver when they took it out. And his huge spleen, also unusual. They decide to keep him for a few more days, then another week just to be sure. Tina visits more frequently. There is a subtle change in tone, a slightly forced cheerfulness in her greeting to us. We see ten degrees more of her back and none of her face when she turns from talking to us to talking with Jesse. The two of them are creating a code from moment to moment in clear view of an illiterate world. Finally the great day comes to take him home, but not without balloons, a cake, and a large gathering of doctors and nurses. Tina is here. Winks are exchanged around the room. The two of them write and call each other and we come by the paediatric intensive care unit (PICU) after his appointments at the liver clinic. One day he makes a phone call to his mother and then has something to tell us. We are happy for both of them, grateful to Tina for taking care of Jesse and, through a happy accident of timing and crisis, helping him through the treacherous passage from adolescence to manhood. We are proud to have her for a daughter-in-law . . .
worried about peritonitis and didn’t want to mask his symp-
toms with fentanyl. I was pissed off at her, at the liver team, at
myself. I wondered if I should ask her to beep Dr Dorand. Jesse
rolled back and forth holding his belly. His face was twisted
and creased. At 11:30, three hours after Carol’s first call, a
surgical resident sauntered in, much as someone Jesse’s height,
rolled back and forth holding his belly. His face was twisted
myself. I wondered if I should ask her to beep Dr Dorand. Jesse
worried about peritonitis and didn’t want to mask his symp-
toms, at least his liver was metabolising them. I had persuaded
myself that Dr Dorand liked Jesse and that his unending
search for a crevice to hammer the next spike into was made
up himself that Dr Dorand liked Jesse and that his unending
search for a crevice to hammer the next spike into was made
up of more than fear of having Jesse’s death logged against
him. Or perhaps our affection for him came from his having
taken the time to talk to Jesse before he was changed. Cindy
had told me in hushed, almost religious tones, that Dr Dorand
wanted to meet Jesse when he came in for his last clinic visit.
It was clear we should regard this as an honour. I tried to pre-
him.

What questions would you like to ask Dr Dorand, Jesse?
I don’t know.
I ask a lot of questions. Maybe it keeps you from asking
questions that you have. After all, it is your body.
Shrug, little smile. I suggested that he ask how long he’d be
in the hospital after his transplant. Also, how long he’d have
to wait after the transplant before he could have an ileoanal pull
through, where they would take his stoma, the round-red-
bulb end of his small intestine that peeked out from the side
of his belly, pull it down, and sew it to his rectal muscles so he
could have near-normal bowel movements again.
Dr Dorand sat behind a large mahogany desk in a tiny room
at the clinic. About eighteen days, if there are no complica-
tions, he said of the hospital stay after transplant. About six
months, he said of the time between transplant and pull
through. His shoulder jerked occasionally as he talked. His
little finger tipped forward and punctuated, by contrast, the
subly pictorial movements of his hands. I noted, pleased with
Jesse’s sense of etiquette, that he did not react visibly to Dr
Rand’s tics. It was odd, but we, his parents, never worried
about Dorand’s ability to perform the most delicate of surger-
ies, although Jesse may have. We assumed that the tics
would be bad. The x-ray showed free air in the abdominal cav-
ity. Dr Rand left, then came back holding a clipboard.
Jesse, we want to take you down to have a look at you to
make sure everything’s OK. This probably won’t hurt you
afterwards.
He signed the consent form. Dr Rand left.
Yay, right, it won’t hurt.
His face showed restrained anger, an unwilling acceptance of
new pain, and a commitment to himself not to be bamboozled.
I wanted to reach him but he was reaching down inside him-
self, and any reassurance I could offer was as hollow as Dr
Rand’s that he would feel no pain. Ellie buzzed in and out to
get him ready to go down.
Don’t wawwwry about it Jess. They do this all the time.
They take you baabaaack. And baaback. And baaback.
She buzzed out of the room.
Rachel and Will arrived. Gail was on her way back from
Naugatuck. They carted him off fully conscious for a second
trip to the OR. We went to the surgical waiting room and took
the same spot overlooking the gift store from the second story
railing. Dr Dorand came in. They had found a hole in his
intestine through done, if you want that. I know I would.
He was reaching out to Jesse, and Jesse was hard to reach.
He just wanted to get it over with and forget about it.
But there is about a seven per cent chance that you won’t make
it.
I looked at Jesse. He showed no reaction.
Dr Dorand stood with us now a few feet behind Jesse’s bed,
as we had taught him. He was ready to go and getting nervous,
but Gail and I had taken positions on either side of him. Gail
asked him what he thought. There was a long silence.
It worries me that he’s not getting better. It’s puzzling. There are no positive cultures. It could be a bacteria or virus we don’t usually see. Or a toxic reaction to medications. Or his spleen. The coagulopathy is bad. I don’t think he’s still infected but the damage is done. And the longer things stay neutral the more things can happen.

Two days later, Jesse’s blood pressure went down during the night. His weight and abdominal girth were up. His stomach was tight as a drum. His intestine was still. They stopped feeding him. The fluid in his abdomen pushed hard at the base of his lungs. His left chest tube, for he had two now, wasn’t draining well. They put in two new IV lines, one in each arm. For the first time there was talk about whether his kidneys would come back. They put goggles on his eyes to protect them from a virus, cytomegloia, that he was at risk for now. Dr Dorand and Dr Lanier, the attending gastroenterologist, came by on rounds. Dr Dorand started.

Jesse’s condition has gotten worse. He probably won’t last more than another day or two.

What will happen? I asked.

They won’t be able to maintain his blood pressure, said Dr Lanier.

Dr Dorand gave me an embarrassed smile and shook my hand. They went on down the hall. Rachel was crying. I put my arm around her, unsure whether I should. We agreed that we should make phone calls, and split up. I was hungry. I went down to the cafeteria and got something to eat. Then I called Gail and went back upstairs. Jesse was bloated, bloated and grey to me in the dark. All the claptrap about saying it’s all right to let go went through my mind, but I couldn’t say goodbye to him out loud. Gail arrived. We sat in the neonatal lounge and talked about the funeral. I wondered if Rachel and I would fight over it.

Postscript: Jesse did not die at this point, but rallied, and had a second transplant. Further complications, including another perforation, this time caused by his weakened condition and reduced nutrition, led to further operations and another bout of sepsis. He died on August 8, 1995, just over three months after his first transplant, but not before a period of several weeks in July when he was fully awake and very much in contact with his family, his nurses, and his doctors.

NOTE

The full version of the memoirs concerning Jesse Rowe, of which the material in this paper is an extract, will be published in: Rowe M. The Book of Jesse, Washington, DC: the Francis Press, 2002 (forthcoming, October).