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.

Transplant: a non-fiction narrative

M Rowe


The phone was ringing, outside, near the kitchen of the Transplant Respite Center where we were staying. I didn't mind taking my turn, but at two o’clock in the morning by the clock next to my bed, whoever knows he might get a call should have the decency to wake up like a shot off a shovel and grab it. I got up, wobbled around the mattress, felt for the doorknob, and made it halfway across the dining room. The phone, like a dull joke, stopped ringing. Now I wondered if it could be for us. Gail came out. My beeper went off in the bedroom. I climbed over the air mattress and around the folding bed to get to the nightstand. I came back out and dialled the room. I climbed over the air mattress and around the folding bed to get to the nightstand. I came back out and dialled the glowing green number on the display.

Paediatric Unit. I gave her my name. She said to hold on. Michael? It was Rachel, Jesse's mother. I called you before but no one answered.

I know. I didn’t get to the phone in time.

Well, I’ve got news. There’s a possible transplant for Jesse tomorrow morning.

I waited. You mean this morning?

Yes. Around 7:00 a.m.

Today? He might have a transplant?

Yes.

How’s he doing?

He’s OK. A little shocked. And nervous. They’re starting to get him ready.

How did this happen?

I don’t know. They just told me a few minutes ago.

So we don’t know for sure?

No. But it sounds likely. They’re getting him ready.

All right, tell him we’ll be right over.

All right. I’ll tell him.

No. But it sounds likely. They’re getting him ready.

We sat in the dark dining room and talked. Twenty minutes might have gone by. We made a plan. Gail called her sister to meet us at the hospital. We woke the children—Daniel and Cassandra, Jesse’s half-siblings. They had slept through all of it, the ringing and beeping and loud whispering, the climbing over folding bed and air mattress. Now I was anxious to see Jesse and get the details from Rachel. We dragged the kids and their bags and whatever we could find that might come in handy for a long day at the hospital and flagged down a taxi on Third Avenue.

Jesse was shaken, paler than usual. They took his blood pressure and started an IV and gave him something to keep him calm. His room was cramped with beds and chairs and family. Nurses and doctors came in and walked out. I sat on the other bed with Gail. An aide came in.
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 it came 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 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 clinic visits to back him up. If calamity struck we would be devastated, but he had been honest and 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 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.

What about his hernia? I asked. It appeared not long after his colitis surgery two years ago. The tendons they cut through to remove his diseased colon didn’t heal together properly. They left a space for his intestine to pop through. The hernia had swelled during the past year until it wouldn’t flatten out when he lay down and pressed his hand against it, as Dr Gardner had instructed him. Dr Boyd seemed amused that I would ask about his hernia when Jesse had just had a liver transplant. But he was nineteen years old. He still had to walk around in the world, didn’t he?

We sewed it up from the inside. We can repair it again later if we need to.

He left to finish up. The contrast in words and tone between the two of them was unsettling. Different approaches, maybe. Dr Dorand's is to calm you down, Dr. Boyd's is to shake you up. The surgery took thirteen hours in all.

We sat in his room after they brought him back and got him settled. We watched him sleep and went out to make good news calls. Dr Atella, the liver fellow, told us that getting a liver so quickly had nothing to do with Jesse being admitted the night before. Patients can’t be bumped up on the list until they've been hospitalised for five days, she said. We would have been called at home if we hadn’t already been here. It was hard to believe that after a year and a half of waiting, he would get a liver within eight hours of being admitted, but there it was.

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, of 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.

He 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. Poor, he was 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, Jess.

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 always thought of surgeons as being hard, clinical, cold. Not this one.

That afternoon he sat in an easy chair. Dr Dorand came by and stayed for a bit.

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 (“SATSs”), 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 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 she 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 transplantation of Psychiatry. I could take the train in Friday morning and come in the afternoon, but I’d be happy for an excuse to pass.

The pain got worse.

Where does it hurt, Jesse?

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 indifferent 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 . . .

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.

Can I have some milk, Dad?
worried about peritonitis and didn't want to mask his symptoms 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, five-four in thick-soled orthopaedic shoes, can saunter.

Why'd it take so long?
It's been very busy in the OR (operating room).

Jesse's in a lot of pain.
He's just had a transplant.

And he has a very high tolerance for pain.
The resident examined him, feeling along his belly.

Where does it hurt, Jesse?
I had encouraged him to give the doctor as much detail as he could when he came. He made the same circular motion over the left side of his belly. The resident said he thought it was gas, or an ileus. Through the window of the vestibule that separated Jesse's room from the hall, I saw him at the nurse's station talking to someone, perhaps Dr Dorand, over the phone. Jesse was moaning. The resident prescribed a bolus, a big dose, of fentanyl. It took a long time to kick in. Around two o'clock in the morning he got some sleep. They kept pumping him up with fentanyl.

The next morning he felt fine. He watched two science fiction movies. Across the hall, Laura Alexander, the little girl with cancer, was watching television. She wore a ski cap. Stuffed animals were piled up high on her bed and helium Get Well balloons stuck to the ceiling. Joan fussed over her. Laura ignored her. She wanted something to eat that she couldn't have. A recreation therapist tried to amuse her with Gameboy. She stared straight ahead.

Ellie, the day nurse, thought Jesse might take a walk. She was stick-thin with short reddish hair, a roving eye, and a Brooklyn accent that could make you think the Dodgers hadn't taken a walk to LA to mix with the beautiful crowd. Jesse didn't like her bossy style and iced her with silence. She wanted something to eat that she couldn't have. A recreation therapist tried to amuse her with Gameboy. She stared straight ahead.

By early evening the pain was back. His breathing was shallow and fast. He was running a fever. He had tachycardia, rapid heart rate. There was bile and blood in his ostomy bag. His stomach was bloated. Dr Rand, a young surgical fellow with a swipe of hair over a large bald spot, came in and examined him. He pushed down on Jesse's stomach. It hurt when he let go. The technician wheeled in the machine and took another abdominal x-ray. A pattern of gas along the winding route of his intestine would be good. Free air at one point would be bad. The x-ray showed free air in the abdominal cavity. 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.

Yeah, 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 out to inside himself, 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 baaack. And baaack. And baaack.

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 from electrical cauterisation four days earlier to cut through adhesions.

You couldn't see it then?

If we had seen a hole during the transplant we would have sewn it up. It may have been so small we couldn't see it, or the course it may have caused a bleed that opened up later.

He told us they had taken out two litres of intestinal contents from Jesse's belly.
The steroids masked the inflammation. We'll probably take him back for a re-exploration in a couple of days to clean him out and check for holes and abscesses.

What will happen now?
He will look bloated. His blood pressure will go down and his heart rate and pulse will go up. He will be intubated.

I had already cancelled my presentation. Someone else would fill in for me. We split up to make phone calls to give family members the news.

Jesse had been in the hospital only two weeks, but we'd grown close to Dr Dorand. Perhaps we thought his vulnerability made him eligible to wield a knife on Jesse. And we could always count on him to give a positive spin on a blizzard of bad news. Jesse's bilirubin was up, but all the blood products he was getting could cause that. If he needed more pain medications, 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 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 prepare 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 about 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 complications, 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 subtly pictorial movements of his hands. I noted, pleased with Jesse's sense of etiquette, that he did not react visibly to Dr Dorand's tics. It was odd, but we, his parents, never worried about Dorand's ability to perform the most delicate of surgeries, although Jesse may have. We assumed that the tics stopped when he worked. Jill, the evening nurse who knew everything about everyone here, confirmed this for us.

We left the office. A few minutes later Dr Dorand met with all of us, Gail, Daniel, Cassandra, and Rachel who had just made it in from work, in a small waiting room. He looked at Jesse.

I have no problem going ahead with a transplant for you. You're young and you have your whole life ahead of you. Marriage, children, or whatever it is you want. And getting the pull 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, cytomegial, 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 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 sec-
ond 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