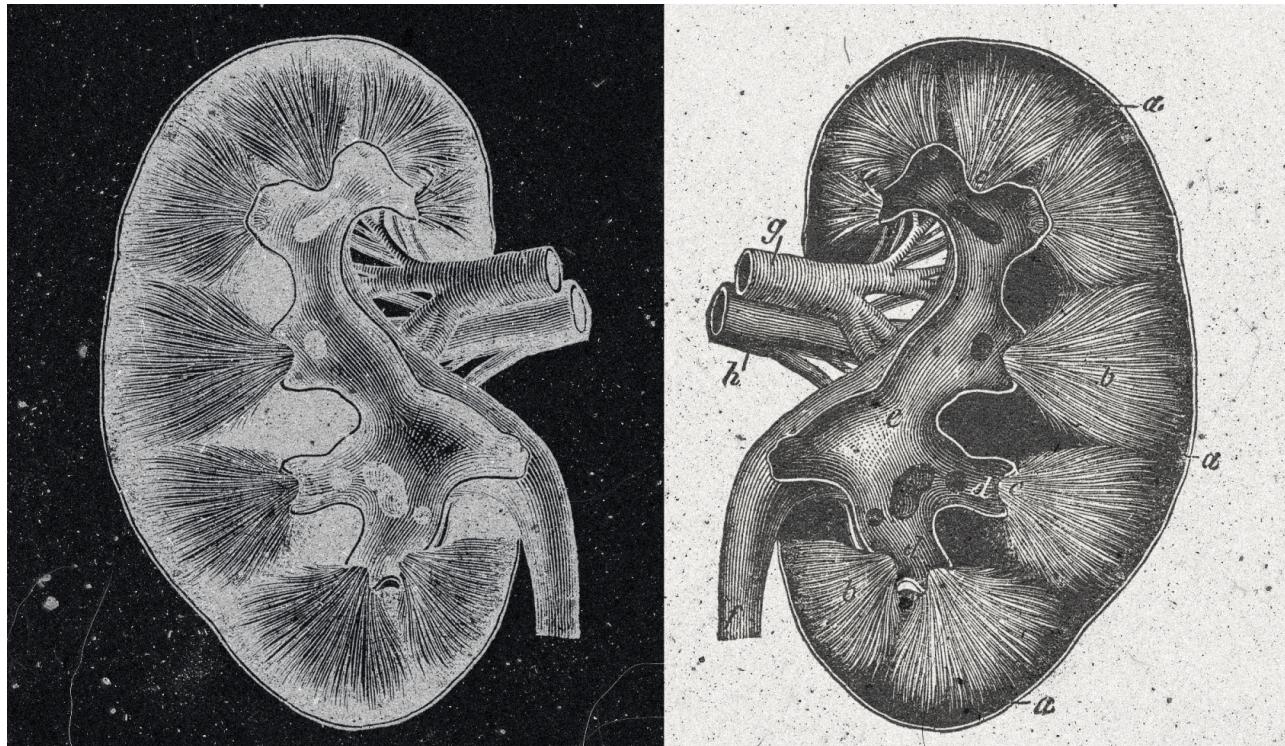


The Organ Transplant Story You Don't Hear

Ten years ago, James "Bo" Calvert received a transplant to replace his only kidney. Now that kidney is failing.



Getty / Collage by Katie Kosma

Katya Cengel | Longreads | November 2018 | 14 minutes (3,847 words)

His arms are covered with the sticky gunk left after bandages come off. There is a blue bruise on the inside of his right forearm. A long plastic tube enters a hole near his belly button. When it's not in use, James "Bo" Calvert tucks the tube that he uses for dialysis into a spandex "bra" that circles his chest.

Calvert has stage 4 kidney disease, which means his kidney function is

only 15 to 30 percent. There are six stages of chronic kidney disease — stage 4 is the last stage before end-stage renal disease (ESRD), when the kidneys cannot filter waste and excess fluid from the blood. At this point, you need a transplant or dialysis to stay alive.

Calvert has had both.

He is 37 and the kidney he received 10 years ago is failing. He has dark hair and pale skin and a day or two of dark stubble. His private room at Norton Audubon Hospital in Louisville, Kentucky, overlooks a forest of mostly deciduous trees. The walls are turquoise, a color that Calvert explains is supposed to induce happiness and calm.

"It's the same color they use in execution chambers," he says.

He isn't being morbid, just factual. Calvert is a bit of a trivia nerd. When he was 21 he was diagnosed with Asperger syndrome, which is on the high-functioning end of the autism spectrum. At 25 he was diagnosed with chronic kidney disease. He learned then that he had been born with only one kidney — and it was failing.

"At this point, you need a transplant or dialysis to stay alive. Calvert has had both. He is 37 and the kidney he received 10 years ago is failing."

After around a year of dialysis, his girlfriend Sara (a pseudonym) donated one of her kidneys to Calvert. While siblings have a 25 percent chance of being an exact match for blood type and antigens, the chances an unrelated donor will be an exact match are only about one in 100,000. Sara was a match — not an exact match, but she had the same blood type and two out of six antigens matched.

When he first got sick, Calvert promised Sara's mother he wouldn't ask for her daughter's kidney. And he didn't. Sara volunteered. She was 24

and wanted their old life back, the life where they went camping and traveling and celebrated their anniversary by riding the Ferris wheel at the Kentucky State Fair. The life they started in college and continued when they moved in together. The life before dialysis.

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Calvert said he hoped the kidney would last 30 years, and his relationship much longer. He and Sara married and bought a house.

In 2017, the transplanted kidney started to fail. Sara left around the same time. After paying Calvert his share, she kept the house and one of their cats, Godzilla. Calvert took the other cat, Donkey Kong, and moved in with his mother. He doesn't seem surprised by his wife's departure.

"I understand why," he says. "She didn't really need to tell me."

As he talks he fiddles with the snaps on the sleeves of his hospital gown. He thinks Sara wasn't ready for another round of dialysis. Sara is not in contact with him and did not want to be interviewed for this story. But she is in contact with Calvert's aunt, Diane Leslie. In a phone interview Leslie explained that Sara still cares about Calvert, but was trying to move on with her life.

"This is not what she thought her life was going to be either," says

Leslie. "She thought they were going to be together forever and maybe have kids."

Ten years ago I wrote about the kidney Calvert received. Like so many kidney donation stories, it had a happy ending, but that ending was premature. That is why I came back in Louisville — the story was incomplete.

It is August 6, 2018, and Calvert has been in the hospital for several days. His Anthem Blue Cross and Blue Shield individual health insurance policy was canceled a few days earlier on July 31. He has Medicare, but it only covers 80 percent of his appointments, procedures, and treatments with no cap on out-of-pocket expenses for ESRD patients under 65.

Calvert is not the only one who falls into this gap. Mike Spigler, vice president of patient services and kidney disease education at the American Kidney Fund (AKF), explains that when private insurance companies would not cover dialysis in the 1970s, Medicare was expanded to cover those with kidney disease under age 65. A kidney transplant is covered, but in a "bizarre unusual quirk" says Spigler, Medicare stops paying for transplant medications for those under 65 after three years. Transplant patients must take immunosuppressant medications for life. They can cost more than \$2,500 per month and prevent the body from rejecting the kidney. If a patient stops taking the medication, they will lose their kidney and return to dialysis.

Before July 31, between Anthem and Medicare, Calvert has always been able to pay for his medication. Without Anthem, he worried he wouldn't be able to afford it and thus would be unable to have a new transplant.

A year of hemodialysis costs around \$88,000, and a kidney transplant costs on average more than \$414,800. According to the AKF, the average annual out-of-pocket expenses for kidney disease patients on Medicare is \$7,000. Medigap plans offered by private insurance companies are designed to make up the difference. Yet 23 states,

including Kentucky, do not require that Medigap policies be made available for ESRD patients. That means there are more than 92,000 patients potentially facing situations similar to Calvert's.

According to Alice Andors, AKF's director of communications, the Fund helped fill the gap by providing \$4 million in financial assistance in Kentucky alone last year, enabling 1,068 transplant and dialysis patients to maintain their health insurance. Medicaid is another option. Although it has limitations, says Spigler, noting that, for example, a patient in Florida who would have to drive six hours round-trip to find a vascular surgeon who accepts Medicaid.

Though the portion of people in the United States with kidney disease, about 14 percent, is not increasing, the overall population is. So there are more people with kidney failure today than 15 years ago, even though the percentage of people with kidney disease has nearly leveled. And those people are living longer. Since 1996, **mortality rates for dialysis patients have fallen by 28 percent and 40 percent for transplant patients**, according to the National Institute of Diabetes and Digestive and Kidney Diseases.

When Anthem terminated his coverage, Calvert was told he could get a Medigap plan through Cigna. The premiums are \$410 a month. He receives about \$1,000 a month in disability benefits. He sent off applications to Cigna and the American Kidney Fund at the same time, hoping he would receive a policy that AKF could help him pay for. He did not hear back from either before he ended up in the hospital.

A few days after his hospital stay, Calvert is home. He likes to tell people he has two rooms in the house, sort of his own separate apartment. His mother, Kay Calvert, 69, offers a tour of the second room. It's at the end of the hall, with bare white walls, a single easy chair, a television, and a shelf stacked with an Atari game console and games. This is the dialysis room. When the time comes, Calvert will do his peritoneal dialysis here. Hemodialysis uses an artificial kidney machine to clean the blood. Peritoneal dialysis removes waste by washing fluid in and out of the belly in cycles. Patients leave the fluid

in for three to four hours at a time, repeating the process four to five times a day. When the fluid is inside him, Calvert can move around — one of the advantages of PD is its portability — but he cannot go too far because after several hours he has to drain the fluid.

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When Calvert first became sick, Kay was ruled out as a donor because of a past kidney stone. Calvert's only sibling had died in infancy. His father died when Calvert was 22. That left Calvert's cousins, a group of men who Kay jokes either have all had kidney stones or are too stoned to donate. One of them is nicknamed Big County, another taught Calvert how to clean a deer carcass. Calvert jokes that when they get together they marvel at the shocks on their new trucks. He has trouble relating: "To me, it's like, 'Yep, there's shocks on the truck.'"

The bicep tattoo Calvert wants is of the video-game character Mario holding a radish. He played *Super Mario Bros.* in his childhood, and he identified with Mario. He might be holding a radish, but he is also confident and powerful, ready to bust blocks.

"He just seems really happy," says Calvert. "That's kind of lame, but I don't want like snakes and skulls or anything like that."

Calvert's conversations are peppered with fascinating and somewhat random facts, figures, and historical tidbits like the fact that there have only been 20 cases of papillary thyroglossal duct carcinoma reported in the past 85 years. He collects antique pocket knives, arrowheads, and fleams, tools doctors used for bloodletting. Before he got sick he worked as a photojournalist. Now he spends his time repairing old

weapons, playing video games — especially games from the '90s like *Super Mario Bros.* — chatting on Facebook with friends, and planning his next big project. He would like to build a house. He has the style chosen, a multistory tiny house with a small footprint. He owns some land as well, but it is not zoned for residential living. He has the desire, but it is not yet clear how the home will become a reality.

"He's got some wonderful hobbies in there," his mother says, gesturing to his room.

Driving around Louisville, Calvert is likely to take a detour to tell stories about some of the more interesting sites. A favorite is Camp Zachary Taylor, an Army training camp from the World War I era that was hit hard by the 1918 influenza epidemic. He likes riding his bike to get around, something he still does when he feels up to it. He can be funny and generous — offering to pay for friends' meals and spending a holiday serving food at a homeless shelter. He can also be self-absorbed, forgetting to clean up after himself. He calls himself a democratic socialist, or liberal, but likes to say there is a bit of "good old boy" in him.

In the hallway of his mother's home is an old black-and-white photograph of a group of men, including a family member, in overalls, standing outside a distillery in rural Kentucky. Further down the hall is a framed pair of baby overalls that belonged to his father. Just to the side is a large portrait of Calvert as a young boy in knee socks, his bangs cut a bit jagged over his forehead.

When Calvert first started having trouble last year, Kay didn't want to believe he was in kidney failure again.

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"I was thinking that, 'No, this can't be happening this soon,'" she says. "Because I expected it to last twenty years when he had a live donor, which is the best kind to have."

The average lifespan for a kidney transplanted from a living donor transplant is 12 to 20 years. A kidney transplanted from a deceased donor usually lasts around 8 to 12 years. Calvert's kidney lasted 10 years, but he was always sick during that time, says Kay. He started wearing hearing aids in 2009. (Kay herself has cochlear implants.) Hospital stays have been numerous, making it difficult for Calvert to keep a job. Even when he isn't sick, he is worried he will be soon.

"He's got this always on the back of his mind, which causes him to have anxiety," says Kay.

Despite her initial disbelief, Kay says this time around she is handling things better because she understands more about kidneys. She talks about creatinine, a waste product found in the blood, and how elevated levels are a way of measuring if there is trouble with renal functioning. Calvert also reports feeling more prepared this time, even though he and his mother are facing it mostly alone, aside from his Aunt Diane. Kay doesn't blame Calvert's wife for leaving. Like her son, she insists she understands her reasoning.

"She's a young person and wants to live a young person's life," says Kay. "And it's very, very hard to live a young person's life and it's very, very hard to be married to somebody who is sick all the time."

Friends have also fallen away.

"It's just like they've gone on with their lives," says Kay. "He's stuck."

In his bedroom Calvert is sorting through a plastic container filled with dozens of prescription pills. His room is decorated like a museum, with antique bayonets displayed above a desk and a ROYAL ARMOURIES LOUISVILLE sign from the Frazier History Museum, where he used to work, covering most of one wall. Donkey Kong, the cat, is snuggled on the bed.

After taking several pills and grabbing a mug of coffee, Calvert drives the red Ford Escape he shares with his mother to a Fresenius Kidney Care clinic. He mentions how he never saw himself living back home with his mother. In earlier instant messages he wrote to me about how alone he feels.

"You know, friends get married, have children, and it seems so difficult to meet people my age," he says. "I don't know where to begin to find my place."

Once he wanted all of that — a wife, children, a house, and a job. Before kidney disease, in 2006, he was beginning his adult life. Then he got sick. After he got his transplant in 2008, he continued his work as a freelance photographer, and even landed a full-time gig for a while. He lasted around a year, then the long hours became too much and he had to quit. Last year, he had a job at the Frazier History Museum. He took the stairs at work, was riding his bike, and did push-ups every morning and night. Then he got pneumonia — twice. His creatinine levels started increasing. His posts on Facebook got darker.

"My energy is quickly leaving my body and I'm losing muscle and weight," he wrote.

In instant messages he wrote that "it has been the worst year of my life" and that "the threat of death is very real." At the same time, he can be light and funny, like when he jokes about a famous surgeon signing his name on Calvert's insides or when he describes feeling like a pumpkin after a heavy rain that has taken on so much water it is about to explode. He is frequently bloated now because his kidney is not able to remove enough fluid from his body.

At Fresenius, Calvert takes his plastic tube out and program manager Jessica Ernst sets to work hooking him up for a flush. They both put on plastic masks, and Ernst washes her hands thoroughly before putting on plastic gloves. She tells Calvert the pain that sent him to the hospital was probably the tube getting stuck. Once dialysis starts, it cushions the tube and the pain should go away. She hooks the tube to a bag of clear fluid that she will flush through him and then empty out. She explains that the tube goes into the abdominal cavity, a bowl that

houses his organs and is lined with small blood vessels. The fluid fills the space and will transfuse the toxin out of the blood into the fluid, which will then drain out into another bag. As the fluid goes in, Calvert squirms in his chair, grabbing the armrests and pushing himself upward.

"It's hurting," he says.

Later, when the fluid is draining, he hugs his midsection to try to help the process along. Draining takes about half an hour.

Ernst mentions how much treatment has improved over the years. She talks about a woman she knew whose father needed dialysis when the woman was a child. The closest clinic was in Indianapolis, more than 100 miles away.

"He ended up dying because they couldn't afford to move the whole family to Indianapolis," she says. "But he also couldn't get to Indianapolis for treatment."

Calvert mentions a great-grandfather, a doctor who had patients with kidney failure lining up to die. Then he moves seamlessly to talking about a job.

"I will be looking for gainful employment after this is all over," he says.

He asks about opportunities at the clinic. Ernst tells him it is possible, a couple patients she knows have come to work for the company. The conversation drifts; both seem to know employment is not going to happen anytime soon.

After a coffee and sugar cookie, Calvert is at Audubon Hospital getting his blood drawn. It takes the nurse 10 minutes to go over his list of medications. After examining Calvert and discussing his most recent hospital stay, his doctor, John Gleason, prescribes yet another medication, this one an antibiotic to deal with an infection around the port where the tube enters Calvert's abdomen.

A few days later, Anthem reinstates Calvert. Anthem's media contact in Kentucky said they could not comment on Calvert's individual case. His new premium is \$379 a month. Gleason says the clinic tries to work with patients to find secondary insurance, but admits there aren't a lot of options. He also explains that the frequency with which Calvert has been in the hospital is not normal and is not all related to his kidney. Some of it is his anxiety.

It is Calvert's mental state that Leslie blames for the breakup of her nephew's marriage.

"A lot of the reason for the divorce was not because of his kidney problems but because of his mental status as far as Asperger's," she says.

As an endoscopy nurse, Leslie has taken care of patients that have had heart transplants and take immunosuppressant medications like her nephew. She has seen patients who have had their transplants for years work full-time jobs and be relatively fine. Calvert, though, has never been fine. His anxiety has resulted in multiple trips to the emergency room, as many as three to four a month in the past few years, says Leslie. Because of the immunosuppressant medications they must take, kidney transplant patients are more vulnerable to infection and disease. They are also at risk of developing acute and chronic rejection and are warned to keep a close eye on their health. According to Leslie, Calvert had trouble distinguishing real emergencies from less serious scares.

"He would call me and say, 'I think I need to go to the ER,' and I couldn't talk him down. His anxiety level just gets to a point where he just won't listen," she says.

Because he is a transplant patient, once he is at the ER, they tend to keep him no matter what, says Leslie. The constant trips to the emergency room wore on his wife, who was both the family provider and caregiver, says Leslie.

"She'd come home and the house would be a disaster. Bo had not picked up anything ... like a teenager type thing," says Leslie. "I think

she was working all day, had a stressful job, and I think she just took it until she couldn't."

Gleason admits treating Calvert can be a challenge because of his anxiety and Obsessive Compulsive Disorder, which add "an extra layer that makes it difficult to cut through." Even without that extra layer, Leslie says anxiety comes with the illness. She has found renal patients as a group to have a high level of anxiety and be difficult to deal with.

"It's a very hard adjustment when they are on hemodialysis or peritoneal dialysis like he is going on," she says. "It's life altering. It's forever."

For Calvert, it has also been isolating. His health and anxiety make it hard for him to keep a job and friends. In some ways, Leslie believes, his constant trips to the hospital may be a way to get attention. When she stopped by recently to bring him dinner, he was so thankful to have someone to talk to that he acted as if it was the best thing that had happened all year, she says. Yet, when his family planned to take him out to dinner for his birthday, he canceled at the last minute, saying he didn't feel well. Sara used to go out to dinner without him because he didn't want to do anything, says Leslie. It is difficult for her to watch her nephew like this.

"He is extremely smart," she says. "His mental smartness overwhelms me."

Yet now, he sits in his room waiting to see what's going to happen while all his friends have moved on in life.

"He tries to keep himself busy, but he sleeps a lot, and I think the sleep is more depression than physical illness," she says.

She admits, though, that now that he is in kidney failure again he swells a lot and has good and bad days. Finding a transplant this time around will be harder. Sara gave him 10 years by donating one of her kidneys. It was something she was very willing to do, says Leslie, who is 66 and has been ruled out as a donor. "She didn't hesitate," she says. "To this day she does not regret it at all."

The next transplant may not last as long. With each subsequent kidney, there is usually a shorter kidney lifespan, says Gleason, sometimes as much as 50 percent shorter. That is because when you lose a transplant you retain antibodies, which affect the kidney, so the more kidneys you get the more antibodies you develop. (Other studies suggest repeat kidney transplant recipients have a similar graft survival rate as first-time recipients.) In Gleason's experience, the most kidney transplants a patient can withstand is about three. The data on dialysis is not much better. The five-year survival rate is about 35 percent.

"That's pretty grim when you think about it," he says.

At present, the wait time for a kidney in Kentucky is around four years. Calvert has not yet added himself to the list.

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