

The Heart Transplant Clinic is ground zero for complicated operations

Charles Cook, the survivor of a horrific car crash and a transplant recipient, says there are no people he trusts more than the doctors of the PMCC

By **Bryan Borzykowski**

IT WAS JUST OVER A DECADE AGO that Charles Cook nearly lost his life for the first time. He was driving on a highway in Georgia, coming home from work, when he suffered a massive stroke and passed out. Like out of a scene from *Dukes of Hazzard*, the car flipped over, landed back on its wheels and then continued to drive for several hundred yards before it somehow stopped on the side of the road. Luckily, no one was hit by the out-of-control car, but the wild crash did cause one passerby to rush over and pull Mr. Cook out of the vehicle. “If it wasn’t so spectacular, no one would have noticed, and I would have just died there in the car,” he says.

The stroke was related to a heart condition that was discovered when he was 17 but remained dormant until that fateful day. Mr. Cook had hypertrophic cardiomyopathy (HCM), a disease that causes the myocardium – the muscle of the heart – to thicken, which can restrict blood flow and impact the heart’s rhythm. While nothing happened until the accident, the stroke set in motion years of heart-related complications and near-death experiences: collapsing in a

restaurant; having his heart massaged back to life on an operating room table; and needing intravenous medication to keep his heart pumping and blood flowing.

Mr. Cook’s decade-long ordeal culminated in a successful heart transplant in May 2016, performed by doctors at the Peter Munk Cardiac Centre (PMCC) and the Multi-Organ Transplant Program at UHN. If it weren’t for the heart transplant team at the PMCC – he’s American but moved to Waterloo, Ont., in 2005 and soon became a patient – and Mr. Cook’s unwavering optimism, he knows he’d likely not be here today. “There are no people I trust more than my doctors there,” he says. “They saved my life.”

MEETING DR. ROSS

As Mr. Cook quickly learned, the PMCC’s Heart Transplant Clinic is ground zero for most of the country’s most complicated

heart surgeries. It replaces about 40 hearts a year in patients from across Canada, and it installs nearly 30 left ventricular assist devices (LVAD), a battery-operated pump that helps the left ventricle deliver blood to the rest of the body. The transplant unit is home to more than just surgeries, though, with doctors and nurses also staying in close contact with patients for their entire lives, starting the moment they get admitted to the unit.

When a patient first comes to the PMCC, the patient will likely meet with Dr. Heather Ross, a world-renowned doctor, heart failure specialist and Managing Director of the PMCC’s Heart Failure and Transplant Clinic. She’ll put people through a number of tests, including a stress test that helps determine how hard one’s heart is working. Not surprisingly, Mr. Cook failed his first stress test. “It was operating at about 30 per cent of where it should be,” he says. “Dr. Ross said that was horrible. I liked that she was telling it to



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BIOBANK

Heart-related research has come a long way over the years, in large part due to the PMCC's Cardiovascular Biobank. The biobank, which was created 16 years ago, stores small portions of heart and blood vessel tissues that doctors and scientists can then use to conduct research into the many cardiovascular diseases that afflict Canadians.

It's at the biobank where some of the country's most important work is being conducted, says Dr. Jagdish Butany, a Cardiovascular Pathologist at the PMCC. For instance, its researchers are extracting DNA and RNA from the tissue to see how genes relate to heart disease. This will one day allow for more personalized medical care where doctors can be very specific on how they treat individual patients, he says. The biobank is also being used to study artificial heart valves and hearts, an area of interest for Dr. Butany.

While the biobank is doing groundbreaking cardiovascular work today, it was originally focused on cancer research. Dr. Butany, though, felt that cardiovascular tissues could also be saved and used in a similar way, so he approached his department to see if he could start saving parts of the heart. "If we were going to do any significant future studies, we had to bank this material," he says. "Fortunately, they let me do it."

As important as the biobank is, it needs more funding for it to continue and grow, says Dr. Butany. Right now, it holds about 20,000 tissue samples, but it could hold much more if it had more resources. "Biobanking is an expensive process because you have to keep tissue for many years without it degenerating," he says. "More donations mean we can keep it going for future generations." •

me straight."

Dr. Ross also remembers that day clearly, but it's not the test that stands out. She recalls her first impression of Mr. Cook. He had an incredible attitude, she says, especially in light of what he was facing. "When you're a young man and are told that you have heart failure, most people get really down because their life expectancy is quite limited," she says. "He had a sense of humour that showed that he was totally engaged in the partnership that's required between the patient and the health-care team. He helped make our job easier."

LVAD INSERTIONS

While many patients are simply monitored by Dr. Ross and her team on a regular basis, others eventually have to be admitted to the hospital for more serious surgery. In January 2015, Mr. Cook went to the hospital for what he thought was going to be a regular appointment. When Dr. Ross did her usual checkup, she knew immediately that something was amiss, he says. "I was tired. I couldn't go upstairs like I used to; I hadn't been feeling that well. She knew it was time."

Mr. Cook needed a new heart, but it takes time to get one. In the interim, he was outfitted with an LVAD, which would help his heart pump blood to the rest of his body. The procedure was performed by Dr. Mitesh Badiwala, cardiac surgeon at the PMCC and Surgical Director of the University Health Network's Heart Transplant Clinic, who also points to Mr. Cook's positive attitude as a reason why he has done as well as he has. When they first met, Mr. Cook was in the hospital's Coronary Intensive Care Unit, hooked up to an IV that was administering heart-stimulating drugs. Every time they tried to wean him off the medication, his heart would fail. "He was in a very dire situation," recalls Dr. Badiwala.

In difficult cases such as Mr. Cook's, Dr. Badiwala assembles a team of about 15 people in the operating room consisting of two staff surgeons, a surgical fellow, an assistant, several nurses, health-care workers who can assemble the LVAD and others. Then there are the health-care workers who help postsurgery,

such as physiotherapists and other nurses and surgeons.

While Dr. Badiwala is often the highest-ranking surgeon in the room, he points out that, unlike other places he's worked, it's not run from the top-down. The team is always talking to each other, always asking each other for advice, and they'll bring in other surgeons to help out, even if it's just to hold an instrument and provide some guidance here and there.

Dr. Badiwala says that culture of togetherness and communication was created by Dr. Ross, who says that the team is so big that it's important to create an environment where everyone knows that no member of the team is more important than anyone else. "As they say in Africa: 'If you want to go fast, go alone. If you want to go far, go together,'" she says.

EMOTIONAL MANAGEMENT

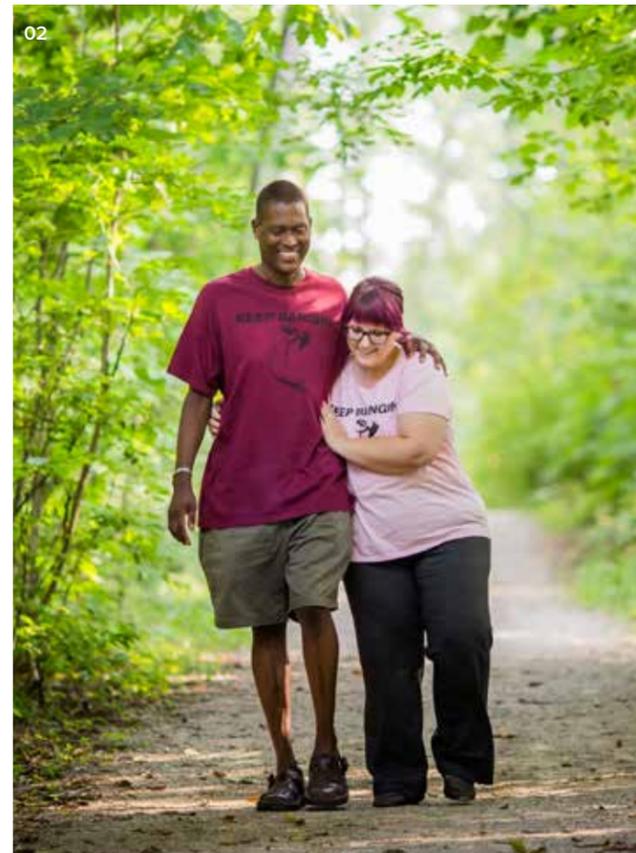
It was all hands on deck with Mr. Cook, who had several complications during and postsurgery: His kidney has failed (he's now on dialysis); he

had numerous infections; his first LVAD was removed and a second one inserted; and he had to stay in the hospital for months.

Heart Transplant Nurse Practitioner Stella Kozusko was one of the nurses who looked after Mr. Cook while he was in the transplant unit. She starts working with patients after they leave the hospital and stays in regular contact with them for life. Ms. Kozusko and her team see patients on a regular basis after their heart transplant to ensure recovery and return to a new life. Changes in breathing, tiredness, fevers and chills are all red flags, and the team teaches patients how to take medication and live a post-transplant life.

Perhaps most importantly, though, they make sure patients are okay. "It's a big emotional process with heart transplants," she says. "These patients know they are on limited time, as a new heart on average lasts for 12 years. It's always in the back of their minds: 'How much more time do I have here?'"

It's this emotional piece that Terry Gill has benefited from the



most. Mr. Gill has been in and out of hospitals for his entire life – he has a congenital heart defect that was discovered when he was born. The 27-year-old New-Wes-Valley, Nfld., resident has had three transplants – two when he was six and one in 2003 – and not surprisingly, his journey has been a difficult one.

While he had all of his transplants at Toronto's SickKids Hospital, he was transferred to the PMCC after he turned 18 and immediately met Dr. Ross and Ms. Kozusko, who started to oversee his care. "They're amazing," he says.

Ms. Kozusko in particular has helped Mr. Gill get through some tough times. Although his third transplant has held up, he's had several infections and flare-ups. They haven't been life-threatening but have resulted in phone calls from him to the transplant office. Every time he phones, Ms. Kozusko picks up. "I know when my body's not right, so I when I'm nervous I like to keep Stella posted on how I'm feeling," he says. She's always been able to calm him down.

The attention that the

transplant program gives to its patients, though, isn't just medical. Mr. Gill often calls just to chit-chat or reveal some good news. On one recent call, he told Ms. Kozusko that he was having a baby. He's also getting married this year – a big milestone for anyone, but especially for someone who wasn't sure he would live into his 20s – and he's invited Ms. Kozusko and others from the transplant team to the ceremony. "I would absolutely love for her to be able to make it," he says.

It's these kinds of calls that keep Ms. Kozusko, and others on the team, going. "I see Terry maybe once or twice a year, but we talk three times a week," she says. "We become their support network – I even talk to his mom. I've seen so much growth and maturity in Terry since he came to us at 18."

Critical to the heart transplant team is the laboratory team and pathologists who help determine the patient's path and progress, before, during and after a transplant. Following a transplant, the patient has a regularly scheduled heart biopsy

(removal of a tiny piece of heart muscle). Its analysis determines the patient's treatment course and medications. Biopsies are interpreted as they are received. Typically within a four-hour time frame, Dr. Heather Ross's team will know if a patient is rejecting the heart graft or if all is well.

THE TRANSPLANT

Both Mr. Gill and Mr. Cook have a determination and a will to live that's been crucial for their survival, but Mr. Cook had to stay particularly strong over the last year as he was waiting for a heart transplant. He was told it could take him up to three years to get one, but a year into his wait he received an unexpected call from the transplant unit. "We think we found a heart that will work for you," recalls Mr. Cook. "I sat down, stopped in my tracks and said: 'Is this legit?'"

It was, and a few days later he had a new heart and, in many ways, a new life. "I feel better than ever, even from before I moved from Georgia," he says. His energy level is higher. His appetite is improving (he shed about 80 pounds off his 210-pound frame after his surgeries and has gained about 20 since the transplant), and he's stronger, too.

While Mr. Cook still needs a kidney transplant, the worst is finally over, he says, and he wants to get back to the life he once had, before the stroke that almost killed him. "It's fantastic," he says. "I can see the end of the tunnel." ▽

01 Dr. Heather Ross, far left, the renowned managing director of PMCC's Heart Failure and Transplant Clinic, shares her insights with visiting Fellows from around the world.

02 Charles Cook and his partner, Monica, are working hard to help him regain the life he had before a stroke almost killed him.

03 Dr. Mitesh Badiwala, cardiac surgeon, examines Charles Cook. Mr. Cook still needs a kidney transplant.

HCM

While Charles Cook's heart problems started with his stroke, his saga really began when he was 17 years old. He found out he had hypertrophic cardiomyopathy, better known as HCM, and was forced out of military school, because any strenuous activity could have landed him in the hospital – or worse.

HCM is a disease of the heart muscle – it's abnormally thickened – and can cause a host of problems, including shortness of breath, chest pains, an irregular heartbeat and sudden death, says Dr. Harry Rakowski, Medical Director at the PMCC's Hypertrophic Cardiomyopathy Clinic.

While Mr. Cook isn't sure how he got the disease, it likely came from one of his parents. In most cases, though not all, HCM is genetic. About one in 500 Canadians has it, though many are asymptomatic and have no idea they have the disease, says Dr. Rakowski, who is leading a global push to change how patients with HCM are managed. He organized the first international HCM summit in Toronto last May.

Most people who have HCM can lead a normal life, minus playing competitive sports. It's often treated with medication, though sometimes surgery is required to remove some of the excess muscle that's blocking the heart. HCM can lead to a stroke in about 4 per cent of cases, and in 1 per cent of cases, it leads to heart failure and a heart transplant, says Dr. Rakowski.

Those who have shortness of breath or chest pains should get looked at – an ECG or heart murmur investigation can uncover the disease. And if a parent has HCM, that child should consider doing a DNA workup to see if he or she has the gene. "Get screened if a parent has it," says Dr. Rakowski. "You could have a 50/50 chance of getting it." •