

Talking about the Gift of Life

Communication approaches can make a difference in choices

DOC TALK

BY STUART FOXMAN

On an early summer's day at the Ottawa General Hospital, Emile Therien was waiting anxiously for the results of the procedure. Days earlier, his daughter Sarah Beth, 32, experienced sudden cardiac arrest. One moment she was healthy and active, the next she was in the ICU in a coma. Now, as a medical team worked, her father, mother and brother prayed.

Not for Sarah Beth's survival. Not anymore. It was too late for that. Mr. Therien and his family had agreed to take her off life support. Their remaining hope for her fate was that her organs could be recovered successfully and donated to waiting patients. Upon learning that the transplants were successful, Mr.



Therien was relieved and so thankful. “You’ve lost your child, but in death at least something positive came out of it,” says Mr. Therien, who has since become an organ and tissue donation advocate, and is also a public member of the CPSO Council.

Talking about organ and tissue donation can be difficult. What are the best ways to raise the issue with families, or with healthy patients who may not know much of becoming donors? Studies show that the right approach by doctors can assist in the decision-making process. ►►

Fast Facts

- Only patients who have sustained a nonrecoverable injury and are on lifesustaining therapy (i.e., ventilator and IV medication to support hemodynamics) at the time of notification to Trillium Gift of Life Network (TGLN) may donate organs.
- Most organ donation occurs after the person has been pronounced dead by neurological criteria.
- The opportunity to donate organs after cardiac death exists when patients do not meet criteria for neurological death.
- Only 1.5% of all patient deaths are eligible to donate solid organs at death.
- The organs that may be donated for transplant include: heart, lungs, liver, kidneys, pancreas, and bowel.
- To provide the best possible support to families and health-care professionals, TGLN requires notification prior to a family discussion by the hospital team regarding withdrawal of life sustaining therapy or testing to confirm neurological death.
- Consultation between TGLN and the health-care team is crucial prior to the donation discussion with the family to provide the best information possible about donation potential.

Source: Trillium Gift of Life Network

Conversations about organ and tissue donation are a “logical part of end-of-life care,” says Dr. Sonny Dhanani, who works in critical care at the Children’s Hospital of Eastern Ontario in Ottawa, and who serves as Chief Medical Officer, Organ Donation, for Trillium Gift of Life Network.

He says there has been a shift in how health-care professionals can frame the conversation. Beyond talking about how one donor can impact other lives (up to eight lives with organs and up to 75 with tissue), the focus can also be on how donations help the family grieve.

Mr. Therien agrees. “All the doctors were concerned about how we would take the loss of our daughter. They were walking on eggshells,” he says. He thinks that doctors can underestimate just how comforting the idea of organ donation can be to families.

Less than a week before Sarah Beth’s cardiac arrest, she had visited her parents. The TV happened to be showing a documentary about organ donation. She casually said that if anything ever happened to her, she’d want to be a donor. That was the first time she had raised the subject.

Emile and Beth Therien were determined to honour their daughter’s wishes. After the family made the decision to

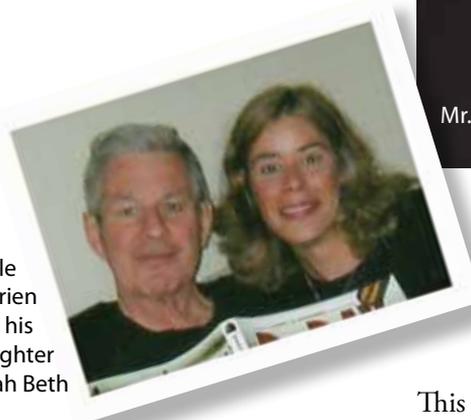
became the first organ donor after cardiac death in Canada.

Three Key Things

Even when people have made their wishes known, families are asked to provide consent before their relative’s organs are recovered, says Dr. Sam Shemie, Medical Director, Donation, Canadian Blood Services. He identifies three key elements when talking about organ and tissue donation:



Mr. Emile Therien



Emile Therien and his daughter Sarah Beth

- 1) be factual;
- 2) be compassionate; and
- 3) don’t be coercive.

withdraw life support, they approached the health-care team with Sarah Beth’s desire to become an organ donor. Sarah Beth Therien

This is a big decision for families, and they need to be informed, said Dr. Shemie. Conversations can include how the potential donations can help other families, the rate of successful transplantation, whether their loved one will be able

to have an open casket or religious concerns.

As for compassion, “It’s amazing how simple things impact on families, how the doctor or nurse treated them, and whether they felt the doctor cared about them and their loved one,” says Dr. Shemie, who works in the Division of Critical Care, Montreal Children’s Hospital, and is Loeb Chair in Organ and Tissue Donation, University of Ottawa.

It’s vital that families not feel rushed or pressured. “If they have an impression you care more about getting consent than you do about them or the person who is dying, that’s not a good message,” Dr. Shemie says.

Thinking early about donations

The burden of having such conversations isn’t all on the critical care team or the physician providing palliative care. In fact, says Dr. Dhanani, “there’s an emotional boundary between doing everything to support life and then talking about donation.”

So who can add to the conversation? Staff from Trillium Gift of Life – doctors, donation coordinators, social workers are all available to answer questions.

“When we get to that end stage, and an experienced person from Trillium Gift of Life has that conversation, the family feels better about it and the consent rate is higher,” says Dr. Dhanani.

The reality in Ontario is that while more than 80% of the public support the idea of organ and tissue

donation, the registration rate is 22%. Though some people might make their wishes known verbally, like Sarah Beth, willing donors should register their consent at www.beadonor.ca.

That registration is crucial, says Dr. Dhanani. Without it, he says that only about half of families will consent to organ and tissue donation by their loved one; with it, more than 90% of families will agree.

Dr. Dhanani suggests that GPs, for instance, can mention organ and tissue donation during a regular physical, as part of a checklist of topics. His best advice is to direct patients to the Trillium Network website, www.giftoflife.on.ca, and urge them to contemplate organ donation now so that their family isn’t burdened with the decision later.

“You’re not trying to sway the patient one way or the other, but most family doctors don’t realize they can make a difference in the process later on by having that conversation now,” says Dr. Dhanani.

Donors leave lasting legacy

Moving the needle on registered consent rates isn’t just up to the health-care field. “It has to be seeded in the public’s mind as a priority,” says Dr. Shemie.

The conversation needs to happen not only in a doctor’s office or hospital, but around the kitchen table, and in schools too. In fact, a number of Ontario high schools have introduced a curriculum on organ and tissue donation (for grades 11-12), through a program developed by Trillium Gift of Life, London Health Sciences Centre and the

Kidney Foundation of Canada.

Not everyone will give their consent. “But many people would with the right person having the conversation and the right timing,” says Dr. Dhanani.



Dr. Sonny Dhanani

Most Canadians expect and hope that a donated organ will be available, for them or their loved one, should the need arise. Yet that can only happen if more individuals and more families understand the legacy of being a donor.

For doctors broaching the subject, “open and honest communication is absolutely critical,” says Mr. Therien. ^{MD}

For clinical questions about organ and tissue donation, or to refer a potential donor, contact the Trillium Gift of Life Network’s Provincial Resource Centre (24 hours a day) at 416-363-4438 or toll-free at 1-877-363-8456.