

He Died Suddenly, but He's Still Helping Others Live Better



FAMILY PHOTOS



The author and her husband traveled more than 5,700 miles on a tandem bike; above, they make a stop in Maine. At left, she gets a ride from him after spraining her ankle during a hike.

By LIBBY CARVEY
Special to The Washington Post

The call came at 3 a.m. last Jan. 20, shortly after we'd gotten home from the hospital.

"Who could that be now?" I asked my grown daughter, Shannon. We looked at the phone and at each other.

"I'll answer it," she said. "Yes, I'm his daughter. Thank you."

She listened, then looked at me. "Dad was registered as an organ donor. They're calling about tissue donation."

"Now?" I asked. "Why on Earth did they call at this hour?"

I felt angry, even though I knew neither of us would sleep that night.

"The tissue is only good for a few hours," Shannon said. "You don't have to say yes. They're very nice. We can talk about it, but they have to know by 8 this morning."

We were both still in shock. My wonderfully fit husband had died less than five hours before of a sudden heart attack at age 56. Organ donation had not come to mind that night, even though Kennan and I had talked about it years earlier when the question first appeared on our Virginia driver's license applications. We'd agreed: We would want our organs to help others if they could. But the question seemed so hypothetical, so . . . distant. Be-

sides, wasn't organ donation an option only in the case of brain-dead people on a ventilator?

The donation specialist at the Washington Regional Transplant Community, the federally designated organ procurement organization for the area, confirmed that Kennan could not be an organ donor because he had died at home and had not been on a ventilator. He could, however, be a tissue donor.

A year later, I know that 98 percent of donors give tissue rather than organs, and that tissue donation is important. One tissue donor can benefit dozens of people, saving the life of a burn victim with skin grafts, giving the gift of sight to one or two people through cornea transplantation, and helping cancer and trauma patients with bone and tendon grafts.

And so, at 3 a.m., we began the painful discussion that more than 2,000 families in the Washington area undertook last year. It went as many such conversations do. We hesitated.

Last year, only 635 families said yes after being called, and I understand why. It was hard to let go, to hand over the body of our beloved husband and father as just a useful hunk of tissue. We couldn't yet really believe he was dead. It all seemed so unreal.

Shannon looked at me. "Dad wanted to be a donor. You both agreed it was the right thing to do. I'll call them."

We had many questions. Kennan's tightknit family included brothers and sisters scattered across several states. We knew they would want to view his body before cremation. Would the body be in any shape to be seen after the donation process? We were assured skin would be taken only from the back of the body, and the team would insert prosthetics where bone was removed and under the eyelids after the eyes were taken out.

This was all painful. We tried hard to think of Kennan's body as no longer Kennan and to comprehend that he was dead.

We had another concern: Would the prosthetics be a problem for cremation, the method we had always planned? That would be no problem, we were told.

Finally, we didn't think family members would be able to get into town for several days, and we did not want to embalm the body. Wouldn't cutting it open hasten decomposition and make a late viewing problematic? The answer to this question was more cautious. We would have to speak to the funeral home about that, the donation specialist said.

We told her to go ahead with the

tissue donation, hoping that everything would work out. We told each other again this was the right thing to do.

But the next morning, the first funeral home we called told us flatly that donation would make a viewing impossible, embalming absolutely necessary and cremation complicated. They were curt and unsympa-

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thetic. I felt sick: Had we made a terrible mistake?

Thankfully, on the advice of a friend, we next called Old Town Funeral Choices in Alexandria. They reassured us that a viewing late in the week would be possible and that cremation would be no problem. We were still nervous, though. Their undertaker told us that without embalming, the body "might not look as we expected" for the viewing. It

might even "smell slightly." We worried for days.

We need not have. Even my 6-year-old grandson, Jeremiah, for whom Kennan was more father than grandfather, was able to see Kennan's body and say goodbye.

And in the days and months since, Kennan's gift has kept on giving, not only to those who have received his tissue but also to us.

At first, it helped just to know we'd done what Kennan had wanted, what he would have considered the right thing. It made our decision and coming to terms with his death a little easier.

A few weeks later, we received a letter from the regional transplant office, offering sympathy and thanks and letting us know that as many as 60 people would benefit just from Kennan's donation of bone. More might be helped by his tendons and skin. Sight might be restored to two people using his corneas.

Kennan's family was here when that letter arrived, and we all cried. It was such a comfort to know that his early death could help so many. When a box arrived with green plastic bracelets for anyone who wanted to show support for organ donation, many family members put them on. And this Thanksgiving, I was touched to see that several nieces and nephews still wear them in memory of their uncle.

Next came a packet for my two daughters and me with a note from Maureen Balderston, the transplant office's donor family advocate, and some pamphlets offering advice and support for the first weeks after losing a husband or a father. I read and re-read those little booklets, sometimes just to feel reassured that what I was experiencing was normal even though it was so awful. Others had gone through this and survived.

A few weeks later, when it was painfully sinking in how permanent my new condition was, I got a phone call from Maureen. She said she didn't want to disturb me but was calling to see how I was doing and if I had any questions. She wanted me to know that I'd be getting letters and occasional phone calls and in-

formation about various support services over the next two years. Unless, of course, I told her I didn't want them.

It was so good to hear from someone who was perfectly comfortable talking about grief. Our friends and family have been a source of enormous support and comfort, but the transplant office is a professional resource to which we can turn, free of charge. There are support groups for my daughters and me and for my grandson. There are speakers and quilt projects and one-on-one mentors, should we want them. And, most important to me this first year, there are the regular letters with their comforting pamphlets.

Kennan has left many gifts, but leading me to the transplant community was an unexpected one. In the year since he died, I have learned that many people don't realize — as Shannon and I initially did not — just how urgently organ and tissue donors are needed. Only 50 percent of eligible donors in the nation designate themselves as such. Even when people do, their next of kin must be closely consulted — which is why we got that 3 a.m. phone call. If the donor hasn't talked to his or her family about the decision, relatives who are overwhelmed after a sudden death often cannot agree to it.

It's understandable. It was hard enough for me to agree even though I knew that Kennan had checked the box to say, "Yes, I want my body to help others when I no longer need it."

But the reluctance of the bereaved costs lives. Of the 635 donors last year, the transplant office was able to use donations from only 391, for a variety of reasons. While the waiting list for organs and tissue has tripled in the past 10 years, the number of donors nationally has stayed more or less constant.

A year from now, the transplant office will tell us how many people were ultimately helped by Kennan's donation. And that will not even be counting his own family.

Comments: health@washpost.com.

DONATION FACTS

- The Washington area has about 2,700 people waiting for organ donations each year.
- About 80 percent of all transplant recipients have active lives five years after transplant surgery.
- Nationally, 18 people die daily while waiting for a transplant, and 120 more are added to the list.
- There is generally no age limit to donation. Tissue from elderly donors has many uses.
- Donation costs nothing to the donor's family or estate.

For more information about organ and tissue donation and how to be a donor, go to www.beadonor.org.

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