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Gift of Hope

Online Donor registry makes organ donation in California much easier

By Sandy Keefe, MSN, RN

On March 7, 2004, a California woman named Lori sat down and penned a note to the family and friends of an organ donor. "My prayers were answered when I got a call that someone donated the perfect lungs for me. I had been waiting 48 months. During that time, I was pretty sick and on oxygen all the time. I am now feeling great... I thank God for every day and for the miracle of life that you gave me."

Today, 18,000 Californians still wait by the phone, praying for that special call that will tell them to come to the hospital to receive a life-saving organ. While one donor can provide organs for up to eight recipients, the refusal rate among families nationwide is around 50 percent. In many cases, family members said they would have agreed to organ donation if they had known the wishes of the potential donor.

On April 4, 2005, organ donation in California became much simpler with the online launch of the Donate Life California Organ & Tissue Donor Registry (www.donateLIFEcalifornia.org for English or www.donateVIDAcalifornia.org for Spanish language registration) for people who live and/or work in California and are 18 or older. Teens from 13-17 years old may register, but their parents will make the final decision at the appropriate time. The registry is confidential, with access limited to appropriate staff members from one of California's organ procurement organizations (OPOs): California Transplant Donor Network (Northern CA), Golden State Donor Services (North Central CA), Lifesharing Community Organ Donation (Imperial and San Diego counties) and OneLegacy (Southern CA).

The Utah Experience

Utah has had a similar donor registry for 3 years, and 68 percent of Utah's adult population have signed up, said Alex McDonald, director of public education for Intermountain Donor Services in Salt Lake City. He explained that the Utah registry had a distinct advantage. "When we first began, we rolled over 950,000 names of people who had said 'yes' to organ donation on their drivers license applications, and notified them of what we had done. Since then, we've attracted more registrants through a public relations campaign on the radio and television, and in the newspapers."

Tracy Bryan, president of Donate Life California, the nonprofit organization that runs the California registry, and a spokeswoman for Golden State Donor Services, agreed that Utah has a huge head start, but is proud of the headway being made in California. "We've launched a media campaign and are doing a number of events to get the word out to the public about the registry."

As more Californians log onto the site and sign up as potential organ donors, hospital nurses will become more aware of the registry as well.

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Karen Burdine, MPA, RN, hospital service coordinator at the California Transplant Donor Network, talked about the role of hospital nurses when death is imminent. "The family needs to see that you are doing everything you can for their loved ones. If an ICU nurse or an ED nurse brings up the topic of organ donation, there is a disconnect on the part of the family. So, we ask the hospital staff to please hold in honor that relationship with the family, and let the nurses from the OPO be the ones who merge with the hospital team and present the donation options to the family members."

Jason Allen, RN, MICN, clinical manager in the ED at Doctors Medical Center in Modesto, instructs his staff to leave the discussion about organ donation up to the nurses from the OPO. "That's a nice division, because it leaves us free to focus on the patient and family, to remain focused on preserving the life of that critically ill or injured individual. Our first priority is, and always will be, patient care. We do everything we can to preserve life."

Burdine summarized the progression that families of potential donors experience. "The patient needs to be first aggressively cared for, and that level of care has to be understood by the family," she said. "If families know their loved one has had the best of our efforts and our energy, then from there, it's a natural progression to say, 'We can't save that life, but can we save another?'"

OPO Staff

Under federal law, hospital staff must notify OPO staff when death is imminent for a patient with a potential for organ donation. Staff from the OPO then usually do a phone evaluation of the patient's prognosis and decide whether to send a representative to the hospital.

At the hospital, the OPO staff member reviews medical records and decides on the feasibility of organ donation. If death is truly imminent, that staff member may approach family members, or a different specialist may be called in from the OPO. In addition to correcting some of the myths and misconceptions about organ donation (see sidebar), OPO staff help the family deal with end-of-life issues. "For the family, the event is death — it's not organ donation. We talk with them about taking the patient off the ventilator, bringing in family members to say a final good-bye, making funeral arrangements and the organ donation process," Burdine explained.

As the Terri Schiavo case has shown, family decisions are much more difficult when the preferences are unclear. Nurses in California now have a perfect opportunity to introduce end-of-life issues through the organ donor registry.

"Decisions about organ donation are best made during times of relative health, rather than during the stressful events that surround the end of life. We want nurses to talk with patients and families, not in the heat of the moment, but in an educational manner ahead of time," Burdine said.

Getting the Word Out

Nancy Allen, BA, RN, CPTC, assistant regional director of OneLegacy described organ donation discussions as a natural part of overall health education. "It's part of our job as nurses to educate people about their choices and the control they can have over their bodies and their end-of-life decisions. By bringing the topic up, you're just educating people about how to ensure their wishes are carried out. It shouldn't be a difficult conversation."

How does a nurse start a conversation about organ donation? "You say to the patient, 'While you're healthy and can think clearly, it's important to discuss the quality of your life and the healthcare decisions you want to make for the future.' And organ donation is one of those decisions," Burdine recommended.

Tamra Grote, RN, RCP, acting executive director of Golden State Donor Services, reminded nurses that education begins at home. "As healthcare professionals, we need to make sure we are talking with our own families about organ donation whenever the conversation comes around to end-of-life issues, or to advanced directives."

The Gift of Life

Burdine described organ donation not only as a gift to organ recipients, but to families of organ donors as well. "The only thing the family can say 'yes' to is the organ donation, because they couldn't say 'no' to death. When they have a chance to allow their loved ones' organs to save a life, they are empowered to make a decision that has a positive outcome."

Nancy Allen shared feedback from families of organ donors that reaffirms the importance of education about organ donation. Every year, her OPO has a recognition ceremony for families and friends of organ donors where the overwhelming emotion is gratitude for having the chance to give the gift of life.

"They never say, 'I made a mistake.' On the other hand, we regularly hear from people who didn't donate, and their comments are along the lines of 'I wish I had understood organ donation better at the time.' It is a very rare and special opportunity to give life to someone else, and it's our job as nurses to educate our patients so they can make an informed decision regarding that opportunity."

Nurses can learn about the registry by visiting the California Transplant Donor Network at www.ctdn.org.

Sandy Keefe is a regular contributor to ADVANCE.

Myths and Misconceptions About Organ Donation

Alex McDonald, director of public education for Intermountain Donor Services in Salt Lake City, shared some responses to common myths and misconceptions about organ donation.

"If I sign up for the registry and am rushed to the hospital, I might not get the best care, or the nurses and doctors might just let me die."

Hospital staff are dedicated to preserving life. They have no access to the registry, and don't even know that you're a potential organ donor.

"If I'm an organ donor, I can't have an open casket funeral."

Organ and tissue donation does not interfere with an open casket funeral.

"My family will have to pay for the organ donation procedures after I die."

There is no cost to the donor family. All expenses are paid by the recipient, usually through insurance, Medicare or Medicaid.

"The recipient may try to contact my family after my death."

For families to meet, both parties have to express an interest in meeting.

"If I have cancer, a heart problem, diabetes, lupus or other health problems, I can't donate organs."

The suitability of donor organs is based on a number of factors, including the general health of the donor and the urgency of the recipient's situation. If you're inclined to be a donor, please sign up for the registry and let the professionals decide at the time of your death.

"I can't donate blood, so I'm not a suitable organ donor."

Most factors that preclude blood donation, such as anemia, don't interfere with successful organ donation.


"I'm too old to be an organ donor."

We will recover organs from individuals up to the age of 80.

"Some religions say that organ donation is wrong."

While some religions prohibit members from receiving organs, all major religions support or permit organ donation.

Sandy Keefe, MSN, RN

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