

# Requesting organ donations: The hardest question to ask

Patricia Houlihan

**D**r. Peter Stone (not his real name) has a thriving practice in an East Coast community of 10 000 residents and would probably be considered a fairly average general practitioner. Like most GPs, he had a basic awareness of the ongoing need for organ donations, but actual involvement in the transplantation process was the furthest thing from his mind until earlier this year, when one of his patients died following cerebral hemorrhage.

Even though the patient had been transferred to a neurosurgical unit in the city, Stone was asked to approach her spouse, who was also hospitalized at the time, to request permission to remove some of his wife's organs.

The neurosurgeon had done the groundwork by keeping the husband apprised of his wife's deteriorating condition, and thus the husband was somewhat prepared for her death. Being prepared to give permission to remove a loved one's organs is a different matter, however. Stone was a little unsure how to proceed — he had never done this before — but he approached the husband, whom he knew well because he was also a patient, matter-of-factly.

"I was surprised he was so receptive", Stone said later. "His reaction certainly makes me more prone to ask the question again. It's like learning to ride a bike. It'll be easier the next time."

For the husband, there's the knowledge that his wife's death helped five other people.

In 1986 the CMA took a major step in the drive to in-

crease the number of organ donations by recommending that doctors routinely record whether brain-dead patients fulfil the criteria established for organ donation and document their approach to patients' families. The

out, the first time is unquestionably the hardest.

A recently reported study involving 124 nurses at six hospitals in metropolitan Chicago provided solid support for a common belief of transplant profes-

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aim, of course, is to ensure that no potential donor is overlooked.

As recently as last year, Canadian statistics indicated that 85% of automobile accident victims who die in hospitals that have more than 400 beds do not become organ donors. Why? The main reason is that attending physicians failed to approach victims' families.

Many physicians who are not directly involved in organ transplantation may pose a problem for organizers of transplant programs — although they recognize the importance of transplantation in the treatment of patients with end-stage organ failure, they don't realize that they have at least two very important roles to play in this process.

The first is to educate patients who are seeking more information on the subject. The second role, and the most difficult one, is to ask grieving families for written permission to remove a loved one's organs.

Most doctors will only do this infrequently and thus experience, that great teacher, is often lacking. But, as Stone pointed

professionals — that the attitude and approach of the person asking the question will have a profound effect on a family's response. The study revealed that a person who considers himself very uncomfortable when asking for an organ donation, as opposed to being sad but confident, will receive a negative response almost 100% of the time. Experience would undoubtedly make physicians more comfortable, but without that behind them, the next best tool is awareness of typical family questions and responses.

Organ procurement professionals in the Multi-Organ Transplant Program in Halifax find that inquiries fall into three general categories:

- Making the decision: Who signs the consent? Can I change my mind? Does my family have to know?

- Concern for my own life: Will everything be done to save my life? If I'm on a life-support system, how will the doctor know that I'm dead? Will organ removal in any way contribute to my death?

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• Procedures: Will the body be disfigured? How will burial and funeral arrangements be affected? Does the donor family have to bear any of the costs of the surgical procedures?

Straightforward answers to these questions have a profoundly positive impact on the attitudes of many patients towards organ donation.

The much more difficult task is to approach a grieving family,

because some family members may still be having trouble accepting that a loved one has died.

Before a physician can develop a positive, confident approach that might result in a positive response, he should examine his own feelings about death and the failure to save a life. This must then be weighed against the possibility of saving or improving several other lives. One difficulty that has been revealed by doctors

who have posed the question is that the recipients of the organs, although real patients, are unknown to them, so it can be difficult for doctors to conceptualize the benefits.

In discussing his own feelings about this death/life conundrum, Stone said: "I can see beyond to the good things in the situation and downplay the bad."

The development of the physician's positive attitude to-

## Transplant drug's effect on appearance can cause noncompliance

David Helwig

Baltasar Gracián, the 17th-century Spanish writer, believed that beauty and folly are generally companions. Evidence of that hypothesis can be found in the tendency of some attractive young transplant recipients to covertly reduce or stop their cyclosporine therapy because of the drug's cosmetic side effects.

Cyclosporine has been linked to adverse reactions, including hepatotoxicity and nephrotoxicity. Hirsutism is a less common and seemingly benign complication, but it is nonetheless highly visible and bothersome to appearance-conscious females.

In some cases, the presence of facial hair is so disturbing to cyclosporine-treated patients that they resort to noncompliance to correct the problem.

At University Hospital in London, Ont., a particularly winsome woman in her late 20s has lost three implanted kidneys because she cannot bear cyclosporine-induced whiskers.

"About one third of patients who get into long-term

problems get into it as a result of noncompliance", says Dr. Calvin Stiller, chief of the multiorgan transplant service at University Hospital.

Stiller and other physicians involved with cyclosporine are quick to point out that hirsutism and other easily noticed side effects such as gingival overgrowth and tremors account for only about 10% of noncompliance cases. The majority of patients who do not follow instructions regarding cyclosporine would have the same problem with any other drug.

Laura Mighton-Eryou, a drug information pharmacist at University Hospital, says it is nonetheless important to prepare patients by warning them in advance about possible complications.

To improve compliance, University Hospital pharmacists spend between 30 and 45 minutes teaching each transplant recipient about cyclosporine and the importance of taking it. The lesson includes a practice session in which patients are taught how to measure their doses.

The patient then starts self-medication while still in the hospital, a routine that nurses monitor. The pharma-

cist also makes a follow-up visit before discharge.

Kathy Schofield, a nurse at the transplant outpatient clinic at Winnipeg's Health Sciences Centre, says that patients who develop hirsutism need reassurance that their appearance is not as bad as they think.

"I do sympathize with them", she says. "They have almost a fine fur on the ears, back, shoulders, everywhere."

Schofield cautions patients against resorting to electrolysis, because introducing needles into follicles could cause a dangerous infection in someone whose immune system is suppressed. Some patients have used mild depilatories on their faces, she says.

On the other hand, some transplant centres are finding that balding men are actually enthusiastic about cyclosporine-induced hirsutism. Nicholas Sinclair, chairman of microbiology and immunology at the University of Western Ontario and an investigator with the Canadian Multi-Centre Transplant Study Group, tells of one renal transplant recipient who was more excited about his new head of hair than his freedom from dialysis.

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wards organ donation can be heightened by the knowledge that a family's altruistic act of agreeing to organ donation can play a significant part in the grieving process. The opportunity to encourage families to offer this life-giving gift may be the only time that a health care professional actually offers concrete help in dealing with death.

Most organ donors have one thing in common — they die unexpectedly. Because of the unanticipated loss, the family tends to have a feeling of senselessness. Organ donation can help restore the family.

There is no standard reaction when the question is posed. Angry responses have been encountered, but these feelings usually give way to charitable ones. Ambivalent responses are common, too, but these are usually replaced by positive ones if understood and dealt with properly.

Much of the ambivalence and resulting difficulty in coming to a decision occurs because the

family is torn between the desire to do something good and its inability to accept the finality of death: Signing the consent form is certainly viewed as the loss of all hope.

Those experienced in handling this situation believe that orienting family members to the reality of the circumstances, giving them information in a sensitive manner and allowing them as much time as possible will all help the family reach the decision that is right for it.

Once a family has made its decision, it needs support. Ongoing communication between family members and a health care professional whom they trust helps them to believe that their decision — whatever it was — was the right one.

During the past 4 years, many transplant programs, as well as government and private task forces, have made numerous recommendations for the development of improved policies and procedures for organ donations.

These have been aimed especially at nontransplant centres, including Canada's hundreds of community hospitals. In June 1986 the Canadian Council on Hospital Accreditation decided that as of January 1987 its Standards for Accreditation of Health Care Facilities would include specific questions relating to organ and tissue donation policies, regardless of the size of the facility.

Many Canadian hospitals are now in the process of fulfilling these criteria. However, the gulf between reading a neatly typed procedure in a manual and actually approaching a family to ask one of life's hardest questions is a wide one.

After his first time, Stone looked at the question from a different perspective. "It may be a new step for those of us in the medical profession, but we have to remember that patients go through new things every time they go into a hospital. I think they're finding it easier to accept than we are." ■

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