

# Why can't we just give, and let live?

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The dearth of organ donations is reaching a crisis point in Europe, but what can be done to improve the situation?

IT GIVES the gift of life and makes sound economic sense, yet organ transplantation in Europe is approaching crisis-point as waiting lists rise and traditional sources for obtaining organs dry up.

Not only are there more people than ever waiting to get a new kidney, heart, liver or lung but their needs tend to be more urgent and their life expectancy without a transplant lower than before.

About 30,000 transplant operations were carried out in Europe last year, more than half of them kidneys. But as advances in medical treatment keep people alive who previously would have died, and lifestyle diseases such as obesity, diabetes and alcoholism increase, the demand for new organs grows yearly.

The figures are stark. Only 10 per cent of people who need a new organ will get one. Across Europe, someone in need of a transplant dies every 10 hours – some 5,500 people each year.

A decade ago, the number of hearts available for transplantation exceeded the number of patients on the waiting list, but today the list is twice as long as the number of available organs.

One of the main brakes on the availability of donor organs is improved road safety. Deaths on the roads traditionally produced a ready supply of organs which were ideal for transplantation, because the victims were young and had suffered brain death. Back in 1995, the average age of donors was 35; today, it stands at 55 and the donor is most likely to have died from stroke.

Counteracting this, the supply of donor kidneys has been improved through the increasing use of living donors. "Donation is an act of love," says Brussels-based Italian Sofia Ciravegna, who has given one of her kidneys to her brother. "I don't feel like a hero. I just wanted to give a daily dose of life to my brother."

Ciravegna says she went through a barrage of physiological tests before the donation could go ahead, but the hardest test was a psychological examination. "I was asked 'What if your daughter needs a kidney? You won't be able to help her' and 'What if your brother rejects your kidney? What will your reaction be?' I replied that I didn't know."

The operation went well for both siblings. "The effect on my brother's life was dramatic. He now has a normal life, works, does sport and eats everything. For me, the only difference is that I have a beautiful scar on my body, which I call my work of art."

Improved techniques allow for the use of organs from older donors and, increasingly, organs are being transplanted from people who died of cardiac arrest; the first such transplant in Ireland was recently successfully carried out.

Organ transplantation is one of the triumphs of modern medicine and it's commonly assumed that the costs involved are huge. However, in many cases, the costs associated with keeping a sick patient alive are even greater. In the UK, the 23,000 people with functioning kidney transplants are saving the health system about £500 million a year, taking into account the cost of the transplant operation and subsequent medication.

For heart transplants, the cost of transplantation is roughly similar to the ongoing costs involved in keeping a patient with a bad heart alive.

But for many patients, not having a transplant simply isn't an option. Only 32 per cent of those on dialysis survive five years; 10-year survival rates are under 10 per cent.

Much of the debate around organ transplants has centred on consent systems; some countries require people to opt out of organ donation after their death, while others, including Ireland, demand specific action by a person to opt in before their organs will be considered for donation. Countries with opt-out systems do tend to have higher donation rates.

"In practice, the consent system doesn't always make that much difference," says Axel Rahmel, medical director of Eurotransplant. "In every case, there will be a dialogue with the family and their wishes are always respected, even where they conflict with the person's wishes.

"Distrust of the system and fear of manipulation of the human body are the dominant reasons for not donating one's organs or those of a deceased close family member," he says.

Donors and their families are often forgotten in the debate on transplantation. For Lia Van Kempen, organ donation was a way of attaching some meaning to her young daughter's tragic death in 2000.

Nine-year-old Kelly suffered brain death after falling down the stairs at the family home. "My child had never done wrong to anyone," Van Kempen recalls. "I said, 'Why is this happening, why is my world falling apart?'"

After the doctor asked if she would donate her daughter's organs, Van Kempen reflected on what Kelly would have wanted. "I was sure she would have said yes herself. I also tried to put myself in position of people with a sick child, but for whom there is no other option than to get a donor."

Kelly's organs were donated to help four children and a 42-year-old man.

Van Kempen, who has set up a support group for people in her position in her native Belgium, says she hasn't regretted the decision "for one minute".

In Ireland, a surge in donations saw a record 248 kidney transplants carried out last year, but only six heart transplants were recorded. More than 650 patients remain on the waiting list.

Spain is recognised as a leader in the area, having tripled donations since 1989.

Rafael Matesanz, who founded the country's organ transplantation system, attributes this success to a professionalising of the service rather than any sea-change in attitudes.

The appointment of donor transplant co-ordinators in hospitals was key to improving donation rates. Matesanz says the interview with the bereaved family is critical, with much depending on the experience of co-ordinators and their skills in the art of gentle persuasion.

Another crucial factor is the degree of public acceptance the transplantation programme enjoys. "There is a significant relationship between public acceptance of what we do as a good thing and donations," he says.

Matesanz eschews public information programmes and advertising campaigns, because his budget is a fraction of that enjoyed by big companies. But he does pay serious attention to the media, in particular the scare stories about organ donation that intermittently appear.

To counteract negative publicity, his officials set up a 24-hour hotline providing information on transplantation to the media and organised meetings between journalists and co-ordinators. It helped that filmmaker Pedro Almodóvar highlighted the issue in two of his films.

Some of these are urban myths – there is, for example, no documented case of someone waking up to find their kidney has been stolen – but they have an impact nonetheless.

“The point isn’t whether stories are true or not, the point is that the coverage causes a marked decrease,” says Matesanz.

### **THE FIGURES:**

Only **10%** of people who need a new organ will get one.

Across Europe, **One** person in need of a transplant dies every **10 hours** that’s **5,500** people each year

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