

SOCIETY

56 000 patients in Europe are on waiting lists for an organ transplant

Hope of a transplant

- ▶ **Every day 10 Europeans die waiting for an organ to save their lives, while seven organs are lost because of a lack of cross-border cooperation. Doctors and patients tell their story**

reports

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"I would like to begin my presentation with a joke, but the subject is not funny," said the German cardiologist Axel Rachmel, Medical Director of the Eurotransplant network which coordinates organ donation between seven European countries, speaking on Tuesday in Brussels at a European Commission seminar for European journalists on the subject of transplantation and organ donation.

And immediately an image appeared on the display screen: it was Father Christmas, clearly annoyed, undergoing dialysis on Christmas Eve and next to him a nurse with folded arms was saying: "I don't care what day it is: four hours is four hours." That was one of the very few humorous notes in a seminar highlighting, ahead of tomorrow's European Day for Organ Donation and Transplantation, the need for Europe to find solutions to the issue of transplants, which are becoming necessary for an increasing number of people worldwide.

The doctor continued with alarming photos and statistics for people at the final stages of disease who could be treated if suitable organs were found early enough for transplantation. In the case of renal failure, for example, where dialysis does not offer the best prospects of survival, and certainly not the best quality of life. Liver failure, which is not always as we think due to cirrhosis of the liver and alcohol but to viral diseases such as hepatitis, which, if left untreated, leads to very painful bloating.

"One in 30 patients dies every day. It's like Russian roulette," said Dr Rahmel. And then there is heart failure, where the number of transplants has gone down because, as the population ages, younger organs are becoming rarer, or pulmonary failure, which patients on the waiting list cannot withstand for long. The numbers speak for themselves: every day 10 Europeans die waiting for an organ to save their lives, i.e. around 4 000 Europeans every year, many of whom could be saved if the national transplant systems and cross-border cooperation in organ donation were improved, since it is estimated that seven organs are lost every day because they are not exchanged between countries.

Emily's hope

Then up stepped a young blond Englishwoman, with a characteristic reddish complexion, Emily Thackray, representing the non-governmental organisation "Live life then give life" for patients on the waiting list for transplantation. She showed photographs of herself when she was a baby, a blond, smiling creature with nothing to suggest that she had been born with cystic fibrosis, a degenerative disease that gradually destroys the lungs. "Growing up as a child, I had to take lots of drugs every day, up to 18 pills a day. I had physiotherapy so that I could breathe. But I went to school and had a good quality of life," she says, and as she tells her story we see pictures of her first as a child and then as a teenager with a portable oxygen machine, until she was confined to bed. At the age of

17, she went into hospital every two months. At university, her lungs were working at 40% capacity. She would go for walks with her friends and spend half an hour gasping for breath. "When they gave me a wheelchair at the age of 20, I was terrified. I wore an oxygen machine weighing 7 kg for two hours. I could not go out much. I spent one month in, one month out of hospital. I spent half my life in hospital and it became my second home," she says. In 2005, when she was 21, she was told that she had 12 months to live and that she would have to have a transplant. "Although I did not have a good quality of life, it was a shock. In England, the waiting list is 18 months and a large percentage of patients die." From that moment she packed her bag, always kept her mobile phone at hand and never went further than two hours away from home: the call to say that suitable organs had been found could come next week, next month or never. "I was not living, simply existing and hoping that someone would be found to give me organs," she says. 22 months went by until the day in January 2007 when she got a call from her coordinator: "We have lungs for you." "I burst into tears, got my mother and by a stroke of luck we were there in one hour. I was very lucky, I knew that I might not live, but I wanted a chance and it had been given to me." The transplant was a success, and Emily, just discharged from hospital, had to learn many things from scratch with her new lungs: how to breathe again and to walk. But it no longer hurts, she no longer feels weak, she can make plans for her life, a husband, a home, work. "A transplant saves not just one life: it affects many lives. I got married and was able to do so because people who were under no obligation to do so said 'yes' to organ donation. That's why I'm here today. In England, 1 000 people die every year waiting for an organ. We can change that and save lives."

Between husband and wife

Organ donation saves many lives, said a couple from the Netherlands, André Beck and José Rutten. José gave one of her kidneys to her husband who had already received a transplant, so the two of them, who have been together for more than 30 years, can talk about the experience from a donor's and recipient's point of view. "It cured not only André, but me. Both of us suffered and were victims of André's disease. As a donor, I feared more for André's health than my own. He was ill, I was not. The difficult thing was to convince him, because giving is easier than receiving," said José.

José gave her kidney to her husband André (photo caption)

Organ donation from a living donor is permitted only in people who are related or with a strong emotional bond. In some countries it is allowed between couples who do not know each other provided that the organs are found to be compatible, and this practice is promoted in Cyprus. The results of taking a kidney from a living donor are much better and patients have better prospects for long-term survival, while donors, statistically, are often in a better physical condition than average, since they are chosen because of their good health, are regularly monitored and learn to follow a healthy lifestyle. In the Netherlands, 50% of transplants are from living donors.

Willing to be donors

In 2010, there were 15.7 transplants per million population from deceased donors and 6.75 kidney transplants from living donors in the EU (4.4 and 26.7 respectively in Cyprus). More than 56 000 patients are on a waiting list for an organ, of whom 5 500 die. 55% of Europeans (63% of Cypriots) declare themselves willing to become organ donors after death. Given that in all countries, the demand for organs exceeds the number of organs available and that demand is growing faster than donation, the EU has included increased organ availability, improving the effectiveness of systems and improving

quality and safety among its priorities. In this context, transnational cooperation in the exchange of organs is being promoted and is already taking place with very encouraging results for organ use in the Nordic countries, Spain and Portugal, and between the Netherlands, Belgium, Luxembourg, Austria, Germany, Croatia and Slovenia.

The Spanish Model

Cadaveric donors, however, remain the main "reserve" of organs for transplantation. When brain death occurs, i.e. when the brain loses its function definitively ("as if the brain has been cut off, there is no circulation and it ceases to function," describes Dr Rahmel), coordinators approach the family and explain the situation, ask them if they would like to donate the organs (from one to six organs) for transplant. "The family trust two people: the doctor and the nurse," says Luc Colenbie, transplant coordinator in Ghent, Belgium.

"In the first conversation with the family we give them information, speak in simple language, in a calm environment. If the family does not understand brain death, they will not agree to donation. We explain that it is an irreversible condition. We give them time to ask questions and we answer them. We listen to what they know about the patient's own thoughts on the matter when he was alive," he says. The relationship that develops between the coordinator and the family is also long lasting: the coordinator must be there to give patients psychological support, but also to inform them in detail about the transplantation of their relative's organs to other patients and to put them in contact with them, if they wish.

We must help them with any administrative formalities relating to death but also keep in touch, sending them Christmas cards, for example. The model in this case is Spain, where last year 32 cadaveric transplants per million population took place - the highest rate in the EU, but it's still not enough to meet their needs. The Spanish Model, explains the director of the Spanish National Transplant Organisation, Dr Rafael Matesanz, is a combination of coordinators, special care and continuous training of hospital staff, the early diagnosis of brain death, the funding of hospitals and cooperation with the media. Dr Matesanz also considers it unnecessary, perhaps even a negative factor, for the public to declare that they will donate organs after death. "This is not about having lists of donors, which is something that pleases only politicians. The point is to invest in donation itself. If a country has a low transplantation rate, never blame the public, blame the system and the willingness of doctors," he says.