

# Journey into the world of transplants: Where it all starts - organ donation

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*'It takes place behind the scenes and often little is known about it, but when one life is lost, medicine can save another. Part one of an investigation into organ transplantation.'*

## *Journey into the world of transplants - Part one*

In July it will be 15 years since he lost his 21-year-old daughter in a car accident. But when he talks on the phone about the race to the hospital, the 100-kilometre motorway journey to Vibo Valentia in



Reggio Calabria, to which his daughter was transferred, the wait for news while surgeons performed brain surgery, and the night and two days spent in intensive care waiting to know his daughter's fate, and his own, Giuseppe Conocchiella recounts the details as if they happened yesterday.

The news that nothing more could be done for Tania, that she was brain dead, came with a proposal, a possibility: to agree to the removal of her organs. 'For us, in that sense, it was easy. My

daughter had always said she wanted to donate her organs if anything should happen to her,' says her father. And so it was. 'Today, whoever received her corneas, mitral valves and kidneys has a better life. Or their life has been saved, like two young people I have since had the opportunity to meet.'

## **Different stories, similar scenarios**

The people and stories may be different, but the scenario is always strikingly similar: an intensive care unit, a man or a woman, sometimes a child, who has ceased to live, their heart still beating, but the electroencephalogram flatlining. It's here that all organ transplant stories begin, when all hope for the person in the hospital bed is lost, but there may be seeds of hope for someone else.

Excluding those families who have experienced it first hand, 'other people' know little about this behind-the-scenes drama of life and death, those few crucial hours in which the family of the deceased, as well as dealing with the tragedy of their loss, must make heart-rending decisions; or how this complex organisational machine which brings hope of life to others is set in motion.

These days, in most cases, the cause of death of organ donors is a devastating brain haemorrhage, head trauma or cardiac arrest. In winter, unfortunately, deaths sometimes occur as a result of carbon monoxide poisoning. And not all organs can always be donated, even with the best will in the world. If the heart has stopped beating for more than 20 minutes, only the kidneys, corneas and other non-impaired tissues can be removed, whereas if the electroencephalogram is flatlining but the heart is still beating, the heart, liver, lungs and pancreas can also be used.

### **The doctor's responsibility**

First of all, the **intensive care doctor** follows the procedures for what is known as pronouncement of legal death. 'Once upon a time a person could be considered dead after a few minutes of cardiac arrest,' recalls Ottorino Barozzi, head of local coordination for the removal of organs at Spedali Civili in Brescia. Today the procedure in intensive care units is longer and more complicated, governed by a law adopted in 1993. If, after performing a series of tests and investigations, the intensive care doctor realises that all is lost, the official procedure to pronounce legal death begins. In the six hours necessary for the final pronouncement, the possibility of donation is put to the family. The decision needs to be taken within that window of time.

A **panel of three doctors**, which must include an intensive care doctor (different from the first one who established the presumed death), a forensic doctor and a neurosurgeon proficient in reading EEGs, carries out a series of checks and also repeats the ones already performed. This is the zero hour.

In the meantime the family, who are probably already aware of the gravity of the situation, are informed. This is one of the most delicate phases. It is often at this point that consent or refusal to donate are decided.

### **The will expressed in life**

The **local transplant coordinator** is the person established by law to manage the situation. He or she is the doctor who will talk to the family and explain what donation is and what it involves. Anyone who does it will agree that it is not a simple task. 'Some regions organise training courses on how to communicate in these situations. In Lombardy we have a **psychologist** in the region who can sometimes help us out, but to a large extent it's down to the individual abilities of the doctor and the hospital,' explains Ottorino Barozzi, who has been doing this for over 20 years. The existing law on donation gives priority to what is known as the 'will expressed in life'. Relatives and friends are asked whether the deceased ever expressed an opinion against organ donation. But the decision is very rarely taken on this basis. A minority of people, around 120 000 across Italy, have expressed their **opinion on donation** during their lifetime, and of those only 10 % are against. A more substantial minority, 1 200 000 people, registered with AIDO, the Italian Organ Donation Association, are definitely in favour. For the other nearly 59 million Italians who might find themselves in such a situation, it will be up to the family **to interpret the will** of their loved one and make a decision. 'In our discussion with the family we try to explain, to argue the value of the gesture. We ask them to testify whether the patient was hostile to donation or whether, conversely, they had expressed a favourable opinion. However, families have almost never discussed the subject and relatives are often unprepared. So we try to dig into the life of the person, to understand and sense what attitude they had towards life and others. It's also important to allow people to give

vent to emotions and feelings,' Barozzi continues. This is one of the few situations in which an **unmarried partner** can also give consent. In the case of minors, the consent of both parents is required.

### **Discussions with the family**

'In my experience, I think it's true to say that a family that agrees to the gift of donation receives an additional consolation compared with one that doesn't. Sometimes I use this argument too. But there's no denying the fact that whether you agree to donation or not, you will live with that decision for the rest of your life,' Barozzi continues.

'It helps families in the grieving process to say to themselves that this death was not meaningless and in vain,' agrees Eufrazio Girardi, donation coordinator at AUSL 3 [local health unit] in Pistoia. 'That's why it saddens me when families refuse, because I know that donation could bring them a little comfort.' Why do relatives refuse? 'The time frame is very tight, some people can't manage to reach a decision in the few hours after the loss of their loved one. But the very next day they might have second thoughts,' Girardi explains. 'In any case, it's important to expand the culture of donation. In our region, going into schools to talk to kids is crucial in conveying the value of this gesture of solidarity.'

While these discussions are going on, time is passing. After six hours, the panel responsible carries out all the checks once again. If they are confirmed, the patient is pronounced dead. For him or her, nothing changes. But if the family has given the go-ahead for the removal of organs, everything will change for someone else (and maybe for the family too). These are matters of life and death that we tend to avoid thinking about. However, purely in terms of probability, as Axel Rahmel, director of the **Eurotransplant** network, often reminds people, 'you are three times more likely to receive a transplant than to be a donor.' Every day, 10 European citizens die while waiting for a transplant, which is almost 4 000 people per year.

The machinery for the allocation of organs is ready. If the family gives the green light, it will start up. If they refuse, everything grinds to a halt.

*(end of part one)*