

Signing for life or death

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'I'm getting very upset, you know? Telling you this. And every time, I'm so traumatised, my blood pressure shoots up. I get so upset.' Elena Bolog is 51 years old and has wept a million tears. Adrian, her 25-year old son, died in May 2010. And on the day he died his mother became one of the 346 Romanians to have signed the document that turns their dead child into an organ donor. Of all the European countries, Romania has the lowest number of people prepared to follow Elena's example. Are Romanians the least generous people in Europe?



[photo: 123rf.com]

Only 34% of Romanians (the smallest percentage in the EU) would answer YES when asked: 'Would you consent to a close member of your family becoming an organ donor in the event of their death?' This question was put to Elena Bolog at the Timișoara Emergency Hospital on the morning of 2 May 2010. It wasn't a pollster who asked her this, but Daniel Iincariu a nurse who is also Timișoara's transplant coordinator. The previous day, Elena received a phone call telling her that her son had been involved in a serious car accident on the road from Ineu to Arad. It was hot, dry day. Adrian was sitting on the back seat. The driver attempted to avoid an obstacle on the road but lost control of the car and it went toppling into a roadside ditch. They were doing around 80 km an hour and the car overturned. Adrian was catapulted through a window and the car fell on top of him.

The duty doctor at the Timișoara hospital wrote on the admission form: massive intracerebral hematoma, severe craniocerebral trauma and major chest trauma. Massive, severe, major. Adrian underwent emergency surgery but his state remained critical. His mother, Elena, was already there.

'They put him on machines until the evening. Later, at around midnight, my husband went home to bed and I stayed with Adi. And then the doctors took him and put him in a tomograph. They let me stay there with him. People said they wouldn't let me stay, but they did let me.' Tanti Neli [Auntie Neli], as she is known to her friends, is a kindly, plump-cheeked lady from Transylvania, who lives in a clean, tidy house in the

village of Beliu, in Arad county. Her husband, who is not Adi's biological father, is a vet and they also have a 14-year old daughter, Adi's sister, Bianca. Adrian Dudas was a graduate of the Faculty of International Relations in Oradea and had been working for some years for an Italian company in Arad. His friends called him 'Dudi'.

'In the morning they put him on machines again, then the doctor came and told me that he had thought he could stabilise him, but too many organs were damaged', says Tanti Neli, a tear blurring the lens of her glasses. The Timișoara Emergency Hospital, where Adrian Dudas was admitted, is one of six hospitals in the country with a dedicated medical staff ready to deal with this kind of situation.

'When a patient no longer has certain reactions, there is a clear protocol stipulating what should happen from then on', explains Daniel Ilincariu, Timișoara's transplant coordinator. It is either the duty doctor or the intensive care doctor who notes that these reactions are absent and who identifies a potential organ donor.

For each patient in a state of deep coma, the doctor has to test for the seven brain stem reflexes, and for spontaneous breathing, and to require that an EEG (Electroencephalography) be carried out in order to show whether there is any brain activity. If all the tests are negative, the doctor then assumes that his patient is in a state of brain death and informs the hospital's transplant coordinator.

'Our main problem is identifying potential donors in a state of brain death. In countries with a higher rate of organ donation, these doctors are paid according to the number of brain dead donors they declare, from whom organs are subsequently harvested. They are paid large amounts of money', says Dr Dan Luscalov, Executive Director of Romania's National Transplant Agency. 'In Romania, however, the doctor whose job it is to inform us that there is a donor is paid nothing. They are doing a job and until 2010 they could have been remunerated by overtime pay. But this method of payment has been blocked by the system since 2010.'



Vascularizare creier normal
vs moarte cerebrală
Foto: sursa: dr. Axel Rahmel

[photo - source : Dr Axel Rahmel]

Blood flow in a normal brain vs brain death

On the morning of 2 May 2010 Tanti Neli was not in church like every other Sunday, but at her son's bedside: 'Nobody else in the room had so many machines attached to them as my Adi. His heart, they told me, was punctured. And his head - they said there was nothing more they could do. His head, completely *kaput..*'. Once Adrian Dudas had been identified as a potential organ donor in a state of brain death, the brain death evaluation protocol was initiated.

This went as follows: Adrian Dudas was examined by three other doctors, an anaesthetist, a neurologist and a neurosurgeon. They performed once again all 12 tests specified in the procedure. Six hours later, each test was repeated for the third time. Daniel Ilincariu, Timișoara's transplant coordinator, was in charge of the whole process.

Romania has only seven transplant coordinators at present and he is one of them. Croatia, with a fifth of the population of Romania, has more than 30 active transplant coordinators. We 'used to have more coordinators in Romania, but they have left the Romanian healthcare system' explains Dr Dan Luscalov, Executive Director of the National Transplant Agency.

'They have either gone abroad, or given up coordinating transplants because of pay. In Spain, regional coordinators dedicate themselves solely to this task and they are very well paid. This is because a coordinator has to be available 24 hours a day' says Dr Dan Luscalov. Spain has the highest transplant rate in the European Union.

'In Romania' continues Dr Luscalov, 'some coordinators are employed by hospitals and some are employed by the National Transplant Agency. In both cases they are employed half time and they are paid very little'. Romania, together with Bulgaria, has the European Union's lowest transplant rate.

[insert: In 2011 Romania and Bulgaria had the lowest transplant figures (heart, kidneys, livers, lungs) in Europe (EU27 + 4). Statistics source: Council of Europe]

The highest salary within the National Transplant Agency (that of the Director) is 440 euros, while the lowest is 130 euros. Timișoara's transplant coordinator, Dan Ilincariu, is one of the 'lucky' ones employed by the National Transplant Agency. 'I am not paid at all for my transplant coordination work. It's very difficult to find a legal way by which to introduce this half-time post, because under Romanian law you cannot add overtime.'

Ilincariu, a slim, pale 41-year old, has been the transplant coordinator for the entire Banat region for seven years. 'The hospitals in Reșița, Arad, Deva, Petroșani and Caransebeș do not have transplant coordinators. There is no one to make a declaration of brain death, no one to maintain a donor who is in a state of brain death. So of course in those hospitals no organs are harvested.' Ilincariu does this coordination for free 'because this way a number of people can be saved and because I am convinced that, at some point, we will get the legislation we need here. But it is difficult to say when.'

It was Dan Ilincariu who asked Tanti Neli the question to which only a third of Romanians would reply YES. 'Then the doctor called me, my husband and one of my husband's cousins. There were five of us in the office: we three, the doctor and Dan Ilincariu. I didn't know him then but later I saw him on television', says Tanti Neli. 'He told us that absolutely nothing more could be done. That Adi was not in a coma, but clinically dead. I couldn't believe it. I couldn't believe it. I couldn't believe that.. suddenly just like that. One day he's fine and the next day.... And he asked me if I would consent to donating his organs.'

'Then the treating doctor withdraws and I stay with the family', says Dan Ilincariu. 'At first the family is in a state of shock. Then they start asking questions and some wish to have a second opinion and we help them contact other hospitals.'

Tanti Neli then left Dan Ilincariu's office and started making phone calls: 'I talked to Adi's father, to his father's brother, to my husband, to the godfather who christened him. He has had kidney problems and had to have a kidney transplant. I also talked to a doctor

in town, who comes from our village. A friend had told him who was in hospital in Timișoara and asked him to come and see Adi. And he came. And he said to me...'. At this point Adi's mother pauses, sighs deeply and one by one she slowly utters the words: 'There is no chance of saving Adi now. It's just the machines that are keeping him alive.'

[insert: No heart transplants have been carried out in Romania since last year because the medical professionals are leaving the country. Nearly all the good ones are leaving.

Dan Luscalov, Executive Director of the National Transplant Agency]

'Once they get the same answer from everywhere and after I too have answered their questions', says Dan Ilincariu, 'as they ask lots of questions, they begin to accept that the patient is in a state of brain death and that this means that the person is in fact dead. And I tell them that the only thing this person can still do here on earth is to help save other lives.'

'I told him straight', says Adi's mother, 'that I don't want him to take Adi's life in order to save other lives. I understand it's a good thing to do, but my son comes first. Then he told me that he had sworn not to take anyone's life.'

A young man of 25, whose friends called him Dudi, died on a sunny day on the road from Ineu to Arad. Two thousand five hundred more Romanians die every year in car accidents in Romania.

'And everyone told me to do what I wished to do. They didn't say 'do it' or 'don't do it'. They all said: "Neli, do what you wish to do." It was a very difficult decision. Very, very difficult. I couldn't understand why nobody ever asked for the father. Everywhere I went only the mother, the mother, the mother.'

Daniel Ilincariu, the transplant coordinator, is also a father. His little girl is six years old. 'It's hard to see a family weeping for their dead child and to remain a pillar of stone. Let's be honest, I am a man and it's difficult for me to admit that I cry. But these moments are very emotional', confesses Ilincariu. 'I cry. Everyone cries.'

And Adi's mother...

'They were saying that if he dies, they throw away the organs after the autopsy anyway. And so, if someone's life could be saved, then why not do a good deed? So that at least...'

And she cries...

'They told me other mothers would be happy, that other lives would be saved. Like this he's still alive in some way for me. I know that part of him is still on earth..'

Then, in the medical office, a form on a white sheet of paper appeared before Adi's mother.

'And I signed. I wrote. All [the organs] were listed, but at admissions they told me that the heart was no good, but the kidneys and liver were.'

When a young person in a state of brain death donates six organs, he gives a total of 55 years of life to six other people. Donating three organs, Adrian Dudas and his mother gave 30 years of life to three other Romanians.

'Do you realise that you're signing for life or death? It's like signing a death sentence for someone you love. Do you realise??? You look up to him like the sun...'

And she cries...

The declaration of consent is five lines long, with standard wording: 'I the undersigned, in my capacity as the husband/wife, parent, adult offspring, brother, sister of the deceased (name), declare that I consent to the harvesting and donation of the following organs and/or tissues and/or cells: I declare that I understand my gesture to be a profoundly humanitarian act and I do not have any claims, financial or otherwise.'

And she the undersigned, the mother, consented.

The administrative procedure for obtaining consent to donate organs in the case of brain death is not the same throughout the European Union. Nineteen countries have a system of presumed consent: in the event of brain death adults of sound mind are presumed to be donors, unless they have previously expressly objected. In the other eight European countries, Romania included, informed consent is required.

The coordinator Daniel Ilincariu says that 'for the great majority of families, signing is a big problem. In Germany, where informed consent is required, the family does not actually have to sign. It's enough to say yes. In Romania, however, everything has to be in writing.'

The National Transplant Agency has been trying for four years to amend the Romanian procedure, but 'the moment we tried to change the law, certain people started a press campaign against the amendment', affirms the Agency's Executive Director Dr Dan Luscalov. 'So as things stand at present, it is the family who decides. Logically you should decide what happens to your organs after your death, not the family. It even got to the point where it was being said that we wanted to kill people in order to take their organs. I cannot tell you precisely who actually launched this press campaign or what their motives were. The result was that the legislative initiative was blocked. Because our Members of Parliament said that this was what Romanians wanted and they want to keep their seats', concludes Dr Luscalov.

[insert: The number of Romanian families who object to a deceased close relative donating organs varies greatly from one year to another. In 2009 62% of families refused while in 2010 only 30% did - half as many. - National Transplant Agency]











Choosing between the two systems of consent is however very tricky, believes the coordinator Daniel Ilincariu. 'Given the situation in Romania, where people know all about every single move made by Gigi Becali but not much about what it means to donate an organ, I think the current legislation is appropriate. The interview gives the family a lot of information, information which they cannot get elsewhere.'

Once the family has signed, Daniel Ilincariu always withdraws for ten minutes: 'in order to calm down a bit.' But not before calling the priest.

The Patriarch of the Romanian Orthodox Church said in 2000 that organ donation is 'a defining gesture for Christians.' In 2007, seven of the main religious groups in Romania stated either that they supported organ donation by donors in a state of brain death or that they left this decision up to the individual.

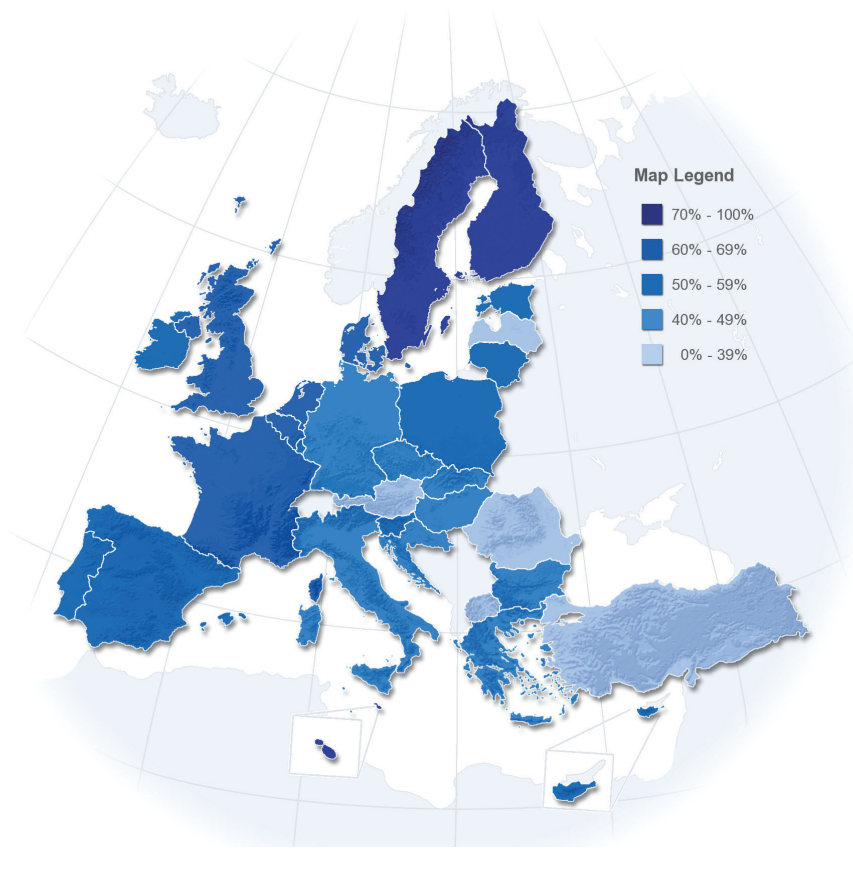
Tanti Neli spoke on the phone with the wife of the priest of the village of Beliu. 'She told me I wasn't doing anything bad and that it wasn't in any way a sin'. Despite all this, Romanians more frequently invoke religious motives (17%) than any other Europeans when they say they object to organ transplantation after death.

However, what people tell a pollster may be very different from the answer they give a doctor at a tragic moment. 'Refusal depends on the manner in which the coordinator approaches the family for the interview', says Professor Rafael Matesanz, Director of the Spanish National Transplant Organisation. 'I have seen that, at the time of interview, the rate of refusal in Spain does not depend on cultural background. The interviewing technique is much more important than religion or prior prejudices. In Spain, Romanian and Latin American immigrants donate at the same high level as Spaniards. Don't try to change a country's mentality, but to professionalise the service for organ donation in that country.'

 SE	73%
 MT	72%
 FI	72%
 BE	67%
 UK	64%
 NL	62%
 FR	61%
 DK	61%
 ES	59%
 IE	58%
 LU	58%
 PT	57%
 PL	57%
 SI	56%
 CY	55%
 LT	53%
 EU27	53%
 EE	51%
 HU	49%
 SK	47%
 DE	46%
 BG	44%
 IT	42%
 EL	41%
 CZ	41%
 LV	36%
 AT	35%
<hr/>	
 RO	34%
<small>* CY (tcc)</small>	52%
 HR	45%
 TR	36%
 MK	32%

Question: QE4. If you were asked in a hospital to donate an organ from a deceased close family member, would you agree?

Answers: Yes



[map - insert: Would you consent to a deceased close relative donating organs
Photo: EuroBarometer, Fieldwork: October 2009 / Publication: June 2010]

The operation to remove organs from Adrian Dudas began on Sunday night, almost 36 hours after the accident. 'The most difficult for me was to let him go in there, in the operating theatre', says Adi's mother. 'I keep asking myself how God kept me standing.'

How did he keep me strong, because my heart was being torn apart. Seeing him in a corridor, he and that bed and I don't know how many machines on wheels and behind him with all the doctors. And waiting for him to go through the door.

And then not seeing him any more. Can you imagine what was happening in my heart and soul? I kissed him and they took him through the door for the operation.'

The operation lasted five hours.

'And then they took him straight to the morgue'.

Two and a half years after the death of Adrian Dudas, the coordinator Daniel Ilincariu no longer remembers the case or Tanti Neli. This may be a form of psychological defence in an extremely stressful occupation. But whereas in western Europe hospitals send thank you letters to donors' families every year and there are support groups for them, no such things exist in Romania.

'We have discussed the issue of thank you letters', says Daniel Ilincariu, 'but unfortunately we have problems, like we cannot buy paper. The hospital budget does not allow for such things.'

The National Transplant Agency does not send thank you letters either.

'You know, we are in a crisis when everyone is trying to economise as much as possible. I think that this should be dealt with by the State and the associations of transplant recipients', adds Ilincariu. 'It's the best way for them to express their gratitude and for us to show we haven't forgotten what happened.'

[insert: In Timișoara we arrange meetings between organ recipients and the families of donors, without them knowing who has had whose organs. But donors still don't have associations, as in other countries. Daniel Ilincariu, the Coordinator]

In the clean and tidy house in the village of Beliu, Tanti Neli shows me where Adi used to sit at table: 'He used to sit here, see?' she says, tapping on a chair with a Bible on it. 'It's like he's gone away and I'm waiting for him to come back. I can't imagine never seeing him again. Let me show you some photos. He also used to wear glasses. These were his glasses', and she points to the frame she is wearing, through which she is looking at me. 'But I've cried so much I can't see any more. And in his glasses frame I put.... I put...'

And she cries...

** All the data and statistics presented in this article come from official national or European sources*

Note: Some of the documentation for this article was produced with the support of the European Commission in the context of the third European workshop for journalists on the subject of organ donation.

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