

# **L'Infirmière Libérale Magazine (ILM)**

June 2012, No 282

"Public health – The gift of life in the community"

# Editorial

## Tomorrow is another day

There are days and then there are 'Days', when our normal calendar, with its pictures of fluffy bunnies or whatever it may be, gives way to a completely different dimension where we are buffeted by a media tide of causes: AIDS, diabetes, global warming... The slogans wash over us like waves on a beach. Last autumn, the ILM was invited to Brussels for a conference of European journalists on organ donation. In all the countries represented, the coordinating nurse acts as the human face of transplantation, liaising between the administration, medical staff and the family. All the testimonies in all the languages have one thing in common: the distress felt by relatives who have no idea what the potential donor would have wanted, because they never talked about donation when the donor was still alive. We started to turn this subject over in our minds and began to wonder about the role you, community nurses<sup>1</sup>, play in the organ donation/transplantation chain in France. Investigating further, we found little time for arguments about the supposed generosity of a "yes" or the supposed selfishness of a "no". Each person's own story determines their relationship with death, their own death, and what happens to their body afterwards. What struck us was the relief experienced by relatives when they are able to answer in unison "he didn't want to donate, he told us so". What we must avoid, at all costs, is the "I don't know", leaving our relatives to live with that uncertainty. As one of our testimonies says, we don't have to wait until 22 June<sup>2</sup> to talk about it. And it's true, we don't have to. But it's a golden opportunity, so we might as well take it.

Candice Moors, Editor-in-chief

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<sup>1</sup> The *infirmière diplômée de l'état en mode d'exercice libéral*, or Idel (freelance state-certified community nurse) is a Franco-Belgian concept (see our dossier "L'appel du large" in ILM No 272).

<sup>2</sup> The 12<sup>th</sup> National Day of Reflection on Organ Donation and Transplantation on 22 June is not the same as the WHO's World Day of Organ Donation (held every 17 October since 2005) and the European Day for Organ Donation and Transplantation, the 14<sup>th</sup> edition of which will be held on 20 October 2012.

## **Dossier**

### "Public health – The gift of life in the community"

While organ donation and transplantation are rarely mentioned in the doctor's surgery, they can still be discussed during home visits or, more spontaneously, in dialysis centres. For patients who have received donor organs or who are on a waiting list, support at home remains essential – but as far as the community-hospital partnership is concerned, there is still room for improvement here

Compiled by Marjolaine Dihl and Candice Moors, illustrations by Jacques Guillet

Every day you visit dozens of homes, people place enormous trust in you, yet nobody ever thinks to give **you** any information. At best, they think of you as a person whose relatives will be better prepared than most – your natural disposition to save lives is already known – to agree to the donation of your organs "if the worst comes to the worst".

It will take a while before organ donation loses its very clinical image of a "specialist, rather isolated activity, a final resort, cut off from activities upstream, and left alone to care for patients after their transplant downstream", according to the Director-General of the *Agence de la biomédecine* (ABM)<sup>3</sup>, Emmanuelle Prada-Bordenave, speaking at a press conference to introduce the new Transplant Strategy. The most important measure in this Strategy for 2012-2015 is to encourage collaboration between hospital and community healthcare professionals. "You can see the gulf between patients who've received a transplant and the others as you walk into a cardiologist's waiting room. But, they have to learn to live together again - and that doesn't cost a thing". There are, in fact, no plans to allocate any specific funding under the Strategy, either for the networks or for the hospitals<sup>4</sup>. According to the ABM, the amount of funding allocated to establishments for transplant activity - granted in lump sums - is less of a problem than the tendency to chip away at that funding. "Some of it gets used to make up for shortfalls in other areas." The involvement of hospital managers, as well as the regional health authorities, appears to be vital if transplant work is to develop.

In the Lorraine region, the Néphrolor network has made progress. While it was originally intended as a network of all the hospital nephrology services of the region for patients suffering from end-stage or pre-end-stage renal failure, it quickly extended into the community, bringing patients with much earlier stage renal failure into contact with "their own doctor and freelance healthcare professionals, such as community nurses, dieticians, psychologists, physiotherapists and pharmacists. They monitor patients on a day-to-day basis, know them well and will always be there for them after the transplant, which is just one of the steps in the treatment process. It's an incredibly valuable resource. When you think that 2 000 patients have received transplants at Nancy Hospital, you realise there's no way the hospital could monitor 1 400 of them on its own," says its President Dr Michèle Kessler. The same type of network exists in Lille and in Bordeaux. It cannot be denied that monitoring transplant patients outside hospital relieves pressure on in-patient staff. Has the time come to recognise the role played by healthcare professionals in the community?

## **LEFT OUT OF THE LOOP**

Since 2006, GPs have been required by Decree to inform young people aged between 16 and 25 of the "consent arrangements for the donation of organs for transplantation"<sup>5</sup>. There is a dedicated doctors' area on the ABM website, and learned societies offer them on-the-job training. Little of that for community nurses, who are lucky if their nursing college offers them a course unit lasting a couple of hours to explain the concept of brain death. So it is not surprising that the community nurses themselves fall prey to certain misconceptions and play down their own role in the donation chain: "It's really a matter

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<sup>3</sup> The health agency which manages all the organ harvesting and donation activities in France, under the aegis of the Ministry of Health.

<sup>4</sup> Regarding the Strategy for 2012-2015, read our news on page 8 of L'ILM No 281.

<sup>5</sup> Decree No 2006-1620 of 18 December 2006.

for young people, for healthy people". In other words, not really their core customers, it has to be said. Furthermore, "it's hard to discuss death with a person who is already ill, you don't have the time to do it well, and that's not what we're there for". These are the words of Michèle Bargin (see ILM No 270), community nurse in Voiron (Isère) and very involved in the harvesting of bone marrow through the association she chairs<sup>6</sup>. "It's harder for me to raise the subject of organ donation with a patient than to talk about bone marrow donation, which is a gift of life from a living donor," she says. "When you talk about organ donation, you're really forcing patients to face the possibility of their own death".

### **First Person**

"When in doubt, say no".

Cristina Malor, former coordinating nurse for donations at Hôpital Foch, today community nurse at Gif-sur-Yvette\*

"For four years, I worked in the lung transplant department of the Hôpital Foch. When my second child was born, I decided to take stock of my life and left the department, albeit reluctantly. For a year, I was responsible for coordinating organ donations, still at the Foch. They called me when a donor was approached, to manage the case and look after the relatives, because the coordinating nurse is the liaison between intensive care, the patient and the family. I was also in contact with the ABM, which keeps the list of persons awaiting transplants, and it was my job to raise the awareness of hospital staff and the nursing colleges... In intensive care, you stay with the donor until the organs have been harvested in theatre, which may take 24 hours. I was prepared for it but, from a human point of view, it can still shake you up sometimes. I've seen so many patients go for the want of a transplant, but there you see families in a state of shock having been told that their loved-one is dead, even though they still look alive... The probability of being able to donate is just 1% and, even then, half the time there will be no donation: when in doubt, they say no. Today, as a community nurse, I can speak freely about these things."

\* Board member of the association *Grégory Lemarchal, Ensemble contre la mucoviscidose* since 2007.

## INFORMING

What sets the record straight? Encounters with patients. At the end of the day, the patients themselves are best able to raise the awareness of community nurses about organ donation. For Michèle Bargin, the pieces fell into place when she began working with a leukaemia patient after a career of more than twenty years. Hervé Chirpaz, a community nurse at Saint-Alban-Leyse, who has been a healthcare manager for one year, had a similar experience: "I opened my surgery 28 years ago. When a dialysis centre was set up in the region, I was immediately interested in the technical aspect. My attitude to donation developed during discussions with persons undergoing dialysis. Then my surgery started taking on cystic fibrosis patients and, there again, the subject of organ donation came up naturally - we didn't necessarily have to make an effort to talk about it", he says. Treating patients with cystic fibrosis changed his outlook – for five years now, he has been on the board of the association *'Grégory Lemarchal Ensemble contre la*

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<sup>6</sup> To find out more about bone marrow donation and the association ADMO 38, please contact Michèle at [admo38@hotmail.fr](mailto:admo38@hotmail.fr) or on 08 71 14 99 35.

*mucoviscidose*' (Grégory Lemarchal, together against cystic fibrosis), named after the young man who came to fame after appearing on Star Academy and who died awaiting a lung transplant. "You can be waiting in the patient's home for an hour or an hour and a half while they're getting their antibiotic drip, sometimes several times a day. And then you bring up the transplant option with the patient and his or her relatives. The more you know about the subject, the more easily you can talk about it. I have two children, and we talk about it with their friends, my friends, colleagues. The only people with whom I don't talk about it are end-of-life patients, unless they bring it up themselves." But community nurses also treat a good number of chronically ill patients. An ideal opportunity to raise the issue with a patient's spouse or relatives, if not with patients themselves.

Even if community nurses do not talk much about donation, it's easier for them to talk about the benefits of transplants. One patient is waiting for a kidney, another one a lung... These conversations make the difference, without the link between donations and transplants being explicitly made. Cristina Malor, who worked as the coordinating nurse for organ harvesting at the Hôpital Foch, summarises it simply: "A surgeon I worked with liked to say that 'even if many people refuse to donate an organ, few will refuse a transplant'. Even in hospital, it's great to prepare theatre for a transplant, but the very idea of organ harvesting often invokes a very negative image, even though the two go hand-in-hand! One colleague was a coordinator for ten years, and had to give it up because she was so exhausted: whenever she turned up in the intensive care ward or the operating theatre, the others would call her 'the vulture'". At the age of 29, Cristina left the hospital to become a community nurse. However, she has not lost sight of her awareness-raising role. "Because I'm quite young, my patients ask me what I did before. I tell them about the life force I saw in my cystic fibrosis patients and about my year as an organ harvesting coordinator. When you've experienced it at such close quarters, it becomes a part of you so it's quite easy to talk about it. Do I talk about death? For me, it's not about that. I just explain that, if you're in favour of donation, you have to tell those around you, because it gives someone else a chance to live as full a life as possible."

## ALL TARGET GROUPS

Whom to talk to? "Nowadays, we can't repeat often enough that we can harvest a healthy kidney or liver from a donor aged 80 years old or older", emphasises Dr Patrice Guerrini, physician assistant at one of the seven regulation and support services of the ABM (see interview below). An 80 year old's kidney will not be used for a youngster of 20, but it may help give a pensioner on dialysis their lost independence back, or hope if the initial transplant is rejected. Dr Karim Laouabdia-Sellami, responsible for medical and scientific policy at the ABM, says "We have perfusion machines that can even improve the quality of the organs we take from ever older patients".

### **First person**

#### **"I had to cope alone"**

Marc Bourlière, heart transplant recipient at the La Timone Hospital in Marseille ten years ago, on dialysis

"It was in March 2002, at the age of 59, that I was called for my heart transplant. It was incredibly emotional - and terrifying. After a few days, the medical team told me it was time to stand on my own two feet. But, even once you have a new heart, you're still anxious, you still wonder if you can cope... I finally got back on track when I was being treated in the rehabilitation centre: a whole new life! But this

new life also had its obligations. I owe so much to the donor. I can't afford to let myself go. When I left the hospital, I had thirty medicines to take every day and I had to learn to manage them all. I was given a booklet explaining the precautions I had to take. I never really called on a community nurse to help me with it. Over the years, after the transplant, I had many health problems linked to the anti-rejection treatment. When I had questions, I preferred to contact my GP, who'd followed me from the start".

## **Interview**

Dr Patrice Guerrini, physician assistant at the ABM regulation and support service Île-de-France, Centre, Antilles, French Guyana

### **"Passing on the message"**

#### **Why are community nurses forgotten in awareness-raising campaigns?**

We certainly do focus our efforts on hospital staff: on intensive care or accident and emergency wards, where donors are to be found... It's true that community nurses are not directly involved in harvesting organs. But we are aware of their role in supporting patients who have received a transplant. And then, we are all potential donors in France through the principle of assumed consent, and that is not sufficiently well understood by the public. Community nurses can pass on the message, but we also know that their time with patients is limited. They visit them to do a specific job, even if it is in our interest for them to bring the right answers.

**But is that still compatible with their role of caring for a mainly elderly clientele, with chronic conditions?** Ah yes, that old chestnut! Today, we can't tell people often enough that yes, we can harvest a healthy kidney or liver from a donor over the age of 80. The recipients are also getting older and older. And, as far as chronic conditions are concerned, if it entails a risk for recipients, we don't use the organs. But this is a group whom we can also inform, and they have family and friends. As citizens, we count on them to pass on the message.

## **Analysis**

### **Paired exchanges – lagging behind Europe**

France is slowly amending its transplant law. For example, in July 2011, the *Assemblée nationale* adopted a bill on bioethics tabled by MP Jean Leonetti concerning paired exchanges of organs between living donors and altruistic donation. These practices "already existed in many European countries [and] do not pose any particular problem", says Arnold Munnich, paediatric geneticist, professor of medicine and advisor to the President of the Republic, during the preparatory work. "This practice is something that people working in the field have called for, and will make it possible for even more transplants to go ahead. We just have to make sure that no pressure is exerted on donors, and the bill gives every guarantee on that point". This should be a step towards the harmonisation of practices at European level.

**In the hospital, if there is clearly indecision and just one relative refuses, then the transplant is considered refused.**

Whilst you have to be less than 50 years old to be entered on the list of bone marrow donors, different criteria and different laws apply to organ and tissue donation. Because

of the principle of assumed consent, only those persons who do not want their organs to be removed should ask to be added to the national refusal register (RNR)<sup>7</sup>. A choice respected by the professionals we met during this investigation: "The hardest thing for families is to find themselves in an emergency situation, in hospital, and not know what their loved one would want them to do. Too many associations criticise people for not wanting to donate, but that's not what donating is about: each person is free to decide on what happens to their own body. On the other hand, those who just won't talk about it deserve to be criticised", says Cristina Malor. In the hospital, if there is clearly indecision and just one relative refuses, then the transplant is considered refused: "We will always respect a 'no'". The donor card? The ABM has only seen 200 since they were brought into service. "I distribute another type of card, with three parts, known as the '*passport de vie*'<sup>8</sup> on which each association places its logo: the person has one in his wallet – which nobody can ever find in the emergency room – and two relatives have a copy, too. It's the best way to ensure that the relatives do not have to make that choice at the most painful moment", says Hervé Chirpaz.

## Testimony

### "It's not just on the 22 June"

Lionel Pfann, Chairman of the *Coordination des transplantés d'Alsace-Lorraine* (Cotral, Association of Transplant Patients of Alsace-Lorraine, [www.cotral.org](http://www.cotral.org))\*

"Our association was created in 1995 with the aim of reducing refusal rates and thus waiting times before transplants. Our aim is to raise people's awareness so that they say what they want, one way or the other. It's not just on the 22 June, National Day of Reflection on Organ Donation and Transplantation, that we need to talk about it! Very often, families do not know what the deceased would have wanted. The refusal rate has been between 30 and 35% for ten years. Holding a donor card is not enough. You have to tell your friends and families. Nurses can also disseminate information about this matter and get people talking. Moreover, in the Mulhouse region, community nurses are asking us for donor cards. Post-transplant, too, they play an important role. They carry out routine care work but they are a source of comfort. That said, the impact of immunosuppressive therapy, which can be very intensive, is little known in medical circles. It should be tackled during training."

## EDUCATING

Whilst organ donation raises a whole raft of difficult issues, transplantation is no less complicated. It is the final stage of a long process. Many months, or even several years, can pass while the patient languishes on the waiting list before being called to the transplant centre for the long-hoped-for operation. And when a transplant does take place, it turns the patient's life upside down, as Marc Bourlière, who received a heart transplant in 2002, can testify. His wallet in his hand, this septuagenarian brandishes two cards: "They're always with me – I have one to say that I have received a transplant and the other to say that I am a donor", he says proudly, before admitting that "keeping it

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<sup>7</sup> For more information, read our section "Votre cabinet" (Your surgery), page 52.

<sup>8</sup> You can get your own 'passport de vie' from the ABM ([www.agence-biomedicine.fr](http://www.agence-biomedicine.fr)), which invented them, or from the following associations: [www.association-gregorylemarchal.org](http://www.association-gregorylemarchal.org), [www.greffedevie.fr](http://www.greffedevie.fr) or [www.france-adot.org](http://www.france-adot.org)

together for all these years has really been a struggle." As exhausting as it is, the battle does not end with the transplant. The 'new life' offered by the transplant involves drugs of all kinds and a long list of dos and don'ts. To cope with it, you need the help of the professionals. The transplant centres provide information to begin with but, once they return home, patients are left to fend for themselves and are in many cases not quite sure that they have understood all the instructions they have been given. In his report "For the rapid, ongoing implementation of therapeutic education (TE)" of June 2010, the deputy for the Moselle department Denis Jacquat puts a figure on this phenomenon. According to his study, "between 22 and 28% of patients who have had a kidney transplant do not take all their medication, risking the rejection of their new organ". This alarming figure prompted the National Health Authority (HAS), in November 2010, to cite therapeutic education as one of the services to be provided for recovering kidney transplant patients<sup>9</sup>.

## **First person**

### **"Nurses are information relays"**

Aurélie Séniuta, healthcare manager in Bordeaux Hospital's kidney transplant service, talks about her experience as a nurse in a dialysis centre.

"When I worked at the dialysis centre at the Bordeaux-Nord Aquitaine polyclinic, we ran therapeutic education workshops during the run-up to the kidney transplant. Occasionally, we would contact community nurses to ask them about the patients' home lives. We would keep them informed about the TE project, and they received the same mail as the doctor. During the therapeutic education (TE) programme, you talk to patients, see how they are getting on, what they know about their chronic renal insufficiency, discuss their social life, family life, relationships, etc. The aim of this conversation is to identify, with patients, the best treatment for them (haemodialysis, peritoneal dialysis, in hospital or at home, transplantation possibilities, etc.). The aim is to help them to decide what fits in best with their lifestyle. The community nurse is not called upon to provide advice but rather is kept informed, like the doctor, so as to be able to prevent any medical or surgical side effects associated with certain dialysis techniques. She is also an information relay to patients."

According to the same document, this task is the responsibility of the nurse, as is the 'provision of the necessary treatment'. It remains to be seen exactly how this will translate on the ground.

To gain some idea, we spoke to Aurélie Séniuta, who works as a healthcare manager in the kidney transplant service of Bordeaux Hospital. "When I have a patient who has received a transplant and is about to return home, if I feel that he cannot cope well with his immunosuppressant drugs, I call on community nurses to prepare them and ensure that he is taking them properly. I do the same for patients who come down with infections and return home with antibiotics." There is no doubt: the nurse, in particular the community nurse, has an important role to play. But she does not always realise how important she is. "I sometimes have patients who have received transplants, but I just take care of the routine things like administering medicines and taking blood... Nothing out of the ordinary", said one community nurse we spoke to. Therapeutic education also

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<sup>9</sup> List of actions and services, ALD 28, "Follow-up to kidney transplants in adults", National Health Authority 2010

seems to be a fairly vague concept. "Nurses often do it without realising they are doing it", says Aurélie Sényuta.

Setting up a real TE programme is proving much more difficult than anticipated, even though the nurses have all the necessary skills. "Only nursing training includes this subject nowadays", emphasises Denis Jacquat in his study. "The training for State-registered nurses teaches the necessary skills to 'initiate and implement health and prevention education', and in particular to formalise and implement therapeutic education. The skills are taught in four course units, with more than 150 theoretical and practical hours spread over the three years of training." In the same study, Denis Jacquat stresses that doctors' lack awareness of "the benefits of TE and the supply available", meaning that they "do not encourage their patients to follow it".

## WHAT PRICE TE?

This is confirmed in the National Health Authority's working document on therapeutic education for chronically ill patients, based on a survey carried out between 2006 and 2007<sup>10</sup>. "In most of the 59 projects surveyed, the number of freelance healthcare professionals involved in therapeutic education was limited." And with good reason: there is no specific budget allocation for it. Even hospitals who do it take the funding from their overall budget. "It will never show up in the PMS," (*Programme de médicalisation des systèmes d'information [Translator's note: System used in the French healthcare system to define the activities of healthcare establishments and allocate an appropriate budget]*), observes Aurélie Sényuta. "We just take the funding from somewhere else... Or not! In fact, if a patient is expensive in terms of treatment time, that's money lost. That's why no one is ever seconded to do TE. You have to keep TE specialists in their department of origin."

"No specific sum is earmarked for therapeutic education" confirms the National Health Authority in its working document of 2007. "According to the people asked, the community nurses working in this area appear to classify these activities as if they were themselves administering the injections". There are also other ways round the current situation. For example, the Néphrolor network, which runs a TE programme known as E'Dire, takes the necessary funds from the *Fonds d'intervention pour la qualité et la coordination des soins* (Fiqs – Intervention fund for the quality and coordination of care). This "allows us to pay these healthcare staff, by way of an exception," says Dr Kessler. "With regard to community nurses, they must have already had general training in TE and put themselves forward voluntarily. They can then receive from specific E'Dire training. They have nothing to do with the dialysis associations. However, some state-registered nurses (in particular in small towns) may be employed by a network." So therapeutic education<sup>11</sup> for transplant patients at home would appear to be in serious difficulties. Despite the *loi HPST* (Hospitals, Patients, Healthcare and Territories Act), which encourages the development of TE, there is still a long way to go.

## In figures

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<sup>10</sup> "Analyse économique et organisationnelle de l'éducation thérapeutique dans la prise en charge des maladies chroniques" (Economic and organisational analysis of therapeutic education in the treatment of chronically ill patients) descriptive surveys (Medico-economic evaluation and public health department of the National Health Authority).

<sup>11</sup> TE will form the subject of the next training supplement of L'ILM, No 283

- 4945 transplants recorded in 2011 (+ 5% compared to 2010).
- 1572 organ harvesting procedures in 2011 (+ 6.5 % compared to 2010).
- Average age of donors: 53.6 years in 2011.
- A total of around 16 000 people needed a transplant in 2011, so around 11 000 remained on the waiting list.

Source: *Agence de la biomédecine*

## **Your surgery: what you need to know**

### **Organ donations - your rights and obligations**

In 2011, the number of refusals in France remained high: 16 000 people were waiting for a transplant and some 5 000 were carried out. Insufficient information, ethical and religious considerations or ignorance of the law? Let's look briefly at the rules on organ donation.

#### **Definitions**

The Larousse dictionary defines an "organ" as "a clearly delimited part of the body of a living organism exercising specific functions", and the website *Vulgaris-Médical* defines it as "an individual part of the body exercising a specific function". The law makes a distinction between organs (heart, lung, kidney, liver, pancreas) and other tissues (skin, bone, cornea, bone marrow, etc.).

#### **Some history**

Ever since the law of 15 November 1887, authorising a person to donate their body, in their will, to a teaching hospital, via the *loi bioéthique* of 29 July 1994, as amended by the laws of 6 August 2004 and 7 July 2011 and the '*loi Cavaillet*' of 22 December 1976, which enshrines the assumption of consent to post-mortem donation, the human body, which is in principle inviolable and unavailable, has been defined in law in order to permit, in particular, the use of its organs in the context of grafts and transplantations.

#### **The principles applicable to organ donations**

Organ donations have to comply with three basic principles.

##### **- Consent**

Everyone is considered to have consented to parts of their body being donated for the purposes of transplantation unless they specifically stated their opposition to this when alive. This is the principle of assumed consent laid down in the *loi Cavaillet* of 22 December 1976 and never called into question. Refusal to donate is an individual decision formalised by entry in the national refusal register (which listed 83 000 people as per July 2011), possible from the age of 13 years. The form must be signed by the person him- or herself and be accompanied by a photocopy of an identity document. This register, managed by the *Agence de la biomédecine*, is systematically checked by doctors when the harvesting of organs is envisaged. The donor card has no legal value: whilst it gives doctors information about the wishes of the deceased, it does not release them from the obligation to talk to the relatives. It should be emphasised that the donation of organs between living persons, limited to the 'family' in the broad sense by the law of 2004, requires that the donor's consent be given before the presiding judge of the 'tribunal de grande instance', once authorisation has been given by a committee of experts.

##### **- Not for payment**

Organ donation is a free act which does not give rise to any payment (apart from the reimbursement of any expenses incurred by the donor or their family). It should be stated clearly that doctors harvesting organs are not allowed to receive any specific fee for this.

##### **- Anonymity**

Apart from cases of direct donations between living persons, or for reasons of "therapeutic necessity", the anonymity rule is absolute. However, donors – or their family – are informed of the purpose of the harvesting and, in certain cases, the result of the transplant.

### **Other rules**

In addition to these three principles, there are other rules governing organ donation, such as the ban on advertising for donors, to the benefit of a specific person or establishment, which does not mean that the public cannot be informed about the purpose of donations; health safety rules, which provide for examinations before any harvesting (clinical selection of donors with checks on their medical history) and bio-medical analyses.

### **Donation: from harvesting to transplant**

Less than 10% of harvesting is from live persons. Article 7 of the amended *loi bioéthique* of 7 July 2011 authorises paired exchanges (described as "when donor A and recipient A turn out to be incompatible, and a second pair B are in the same situation, the possibility of a donation from donor A to receiver B is considered") as well as donations within an extended circle of friends and family ("anyone with a close and stable relationship with the patient for at least two years"). But the majority of donations come from donors in a state of permanent cardiac and respiratory arrest (law of 21 April 2005, adopted 2 August 2005), and, in particular, from donors who are brain dead (nerve cells in the brain irreparably destroyed as a result of lack of oxygen). Treated by competent teams (for example in the emergency room), these are patients for whom all efforts at resuscitation have failed.

Whilst there is no legal definition of death, it is possible to use as a basis the decree of 2 December 1996\*, which provides that the ascertainment of death prior to the harvesting of organs, tissues or cells for therapeutic or scientific purposes must be based on the simultaneous presence of three clinical signs: total absence of consciousness and spontaneous movement, absence of all brain stem reflexes (pupil responsiveness, corneal reflexes, etc.) and total absence of spontaneous breathing. The clinical diagnosis of brain death is confirmed by an additional examination: two electroencephalographies (EEGs) at intervals of four hours, or a cerebral angiography (arteriography or angiography scan, showing that brain vascularisation has stopped).

### **Extra Info**

#### ■ Minors or persons under guardianship?

The harvesting of organs from a minor or a person under guardianship requires the written consent of both parents, in the first case, and of the guardian (plus the supervising judge) in the second. The harvesting of organs in the context of living donations is prohibited for this category of donor (barring certain very rare cases of donations between siblings).

The diagnosis of brain death, for the harvesting of organs for therapeutic purposes, must be co-signed on a legally valid report by two doctors. Breathing and cardiac activity are maintained artificially using resuscitation techniques for a limited period for the purposes of the organ harvesting. It should be emphasised that the doctor certifying death must not be involved in the transplantation activity.

Once death has been certified and the harvesting of tissue or organs considered, the next step is to check on the national refusal register whether the person has refused to be a donor. The relatives are then consulted. Once consent has been given, the doctor can refer to the national list of patients awaiting a transplant, categorised by the type of transplant. The priority rules (laid down in a decree of 24 November 1994) were drawn up on the basis of a system taking many criteria into account (imminent threat of death, age, compatibility, etc.). The organs must be checked and examined, as mentioned above. Patients receiving transplants must also be given specific medical treatment (decree of 9 October 1997).

Harvesting can only take place in establishments authorised by the *Agence de la biomédecine* to that effect, by doctors and healthcare teams specifically trained to do so. However, in some cases surgeons may harvest organs in unauthorised establishments, as long as they are part of a network. It should be remembered that the *loi bioéthique* of 2004 makes organ harvesting a priority mission for hospitals: "All healthcare establishments, whether authorised or not, shall participate in organ and tissue harvesting as members of networks to that effect" (Article L.1233-1 of the Public Health Code). It should be mentioned, lastly, that harvests from living donors must be carried out in transplantation facilities.

Once the organ(s) have been harvested, the body, prepared and re clothed, is returned to the family, in accordance with the deceased's wishes. Moreover, the costs of transferring potential organ donors are borne entirely by the hospital that harvests the organs (Article R.1211-10 of the Public Health Code). ■

VERONIQUE SOKOLOFF, LAWYER, and CANDICE MOORS, JOURNALIST

\* The decree can be consulted at <http://petitlien.fr/5x3> Also see our dossier starting on p.18 "The gift of life in the community"

FIND OUT MORE

■ To request a donor card or a form for entry on the national refusal register, telephone: 0800 20 22 24\*.

\* freephone number of the *Agence de la biomédecine*.

## **GUIDE**

### **EGG AND SPERM DONATION**

Donations are needed to treat certain cases of infertility. Whilst sperm donation is fairly common nowadays, egg donation is another solution.

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#### **I want to donate, but how?**

In France, egg and sperm donations are governed, like the donation of any other parts of the human body, by the *loi bioéthique* of 6 August 2004, as amended by the law of 7 July 2011. They are carried out by competent practitioners in authorised centres and are subject to three main principles: they are voluntary, free and anonymous. To be a donor, you just have to meet the following conditions: be in good health and under the age of 37 (women) or 45 (men).

#### **What happens before the donation?**

In practical terms, the donation has several steps, some of which are common to both types of donation. At an initial interview, donors are informed of the practical arrangements and the legal consequences (in particular with regard to filiation). Women donors also receive medical information about undesirable side effects and possible complications.

#### **Questions/answers**

##### **Do you have to have had your own children to be able to donate your eggs or sperm?**

No, this condition was scrapped by the law of 7 July 2011. Nevertheless, Article L.1244-2-3 of the Public Health Code states that donors "shall then be offered the possibility of having some of their gametes taken and preserved with a view to their possible future use in their own fertility treatment".

##### **I am considering egg donation, but would have to attend the examinations during working hours. Am I entitled to any type of special leave?**

Pursuant to Article 1244-5 of the Public Health Code, you may, if you work, take advantage of special leave of absence from your employer to attend the examinations and the necessary appointments for the stimulation of your ovaries and the harvesting of the oocytes, without loss of pay (Article 1225-16 of the Labour Code).

##### **Can a child born as a result of an egg or sperm donation request that the anonymity of the donor be lifted?**

This issue was debated for many months before the law was adopted on 7 July 2011. But this possibility was rejected, which means that anonymity remains the rule.

### **I am not part of a couple. Can I still donate an egg?**

Yes. One of the major changes in the law of 6 August 2004 was that potential donors no longer had to be part of a couple.

### **Must a donor's partner give their consent to the donation?**

Article L1244-2-1 of the Public Health Code states that "the written consent of the donor and, if he or she is part of a couple, of the other partner, must be obtained." It should be emphasised that the concept of a 'couple' is not defined by law, so a 'partner' may be a spouse, an unmarried partner or a civil partner.

The consent of donors, and any partners, are obtained in writing, on a form. Clinical and biological examinations are carried out, and more specifically for donors, their blood group is determined, and a serological test, a genetic consultation and a karyotype test are carried out. A consultation with a psychologist or psychiatrist, with the donor's partner, if applicable, is also obligatory.

### **Organisation of the harvesting**

For egg donations, the ovaries are stimulated for between 10 and 12 days by way of subcutaneous injections administered by a nurse. During this stimulation, regular blood samples and ovarian echographies can monitor response to the treatment. 35 to 36 hours following the last injection the patient is hospitalised for one day and the eggs are harvested through the vagina, under analgesic or anaesthetic. After donation, the eggs are transported to the laboratory for in-vitro fertilisation on behalf of recipient couples whom the donor does not know. All expenses associated with the donation are covered.

Donated sperm is placed in a straw or vial and frozen. Following several tests (thaw tests, serological tests), and after a minimum of six months, it is distributed to recipient couples with a view to fertility treatment (in vitro insemination or fertilisation). ■