





This publication aims to provide accurate information about organ donation and transplantation as part of building a culture of solidarity in our region.

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For many people who suffer from a variety of diseases, transplantation is the only treatment that can save their lives: think of people with heart disease, respiratory insufficiency or impaired hepatic function.

For other people, organ transplantation is a chance to heal from serious diseases: take, for example, patients on dialysis and how their quality of life could change after a kidney transplant, people with serious eye diseases that can regain their sight with corneal transplantation, but also those who need "new" tissue such as bone segments and tendons, heart valves, vascular segments, skin.

Transplantation may only be performed if, when someone dies, their tissue and organs are donated. Anyone can give consent to donate their organs after death.

People can also be living donors: they can donate blood or other cells, such bone marrow or cord blood cells (from the umbilical cord), giving hope to many people with severe forms of leukemia.

Kidney, heart, liver, intestinal/multivisceral, lung, and pancreas transplants are regularly carried out in our region, as well as transplants of corneas, bone segments, cartilage and tendons, heart valves, skin and vascular segments.

#### **HAVE YOU EVER WONDERED...**

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### How do doctors know that a person is really dead?

They carry out several clinical and instrumental tests that allow them to simultaneously detect:

- state of uncosciousness
- absence of reflexes and reactions to painful stimuli
- absence of spontaneous breathing
- absence of brain electrical activity (the so-called "flatline").

These tests are carried out after the intensivist has reported a patient's possible state of brain death to the hospital's health department.

At this point, the health department is required to convene the "Commission for the determination of death", which consists of three physicians (a medical examiner, an anesthesiologist/intensivist and a neurologist specialising in electroencephalography) who gather at the patient's bedside. If the Commission agrees on the patient's brain death, an observation period will begin to confirm this condition. Physicians will carry out all tests and exams required to certify the state of brain death (irreversible cessation of all brain functions) as required by Italian law no. 578 of 29 December 1993 and Decree of the Italian Ministry of Health no. 582 of 22 August 1994. These tests and exams are repeated twice during the 6 hours of observation for patients of all ages, according to the Italian Ministerial Decree of 11 April 2008.

At the end of the observation period, life support should be discontinued by law. In the case of organ donation, the body is kept on ventilator support until organs and tissue are removed in the operating room. If no organs are donated, artificial ventilation must be suspended immediately, the heart will stop beating in a few minutes, and the body will be taken to the morgue.



# Why do brain dead patients look as if they were breathing while in the ICU?

This impression is created by the ventilator: it blows oxygen and air into the lungs through a tube placed into the brain-dead patient's trachea (inspiratory phase); then, the ventilator cyclically stops and respiratory muscles passively return to their resting position (expiratory phase).



#### Can someone be mistakenly declared dead?

No, they cannot. Every case of brain death, initially reported by the intensivist, is carefully evaluated by three medical specialists in the "Commission for the determination of death". The checks carried out during the Commission's first meeting at the patient's bedside make it possible to certify with absolute certainty the simultaneous presence of all the clinical conditions laid down to define brain death: the observation period will begin only in this case. Otherwise, if the patient proves to be alive, he/she will be kept in intensive care. Sometimes, press and television reports announce "miraculous" news, thoughtlessly confusing a state of "coma" with "brain death".

In some countries, after long legal processes, a court may issue an order to discontinue life support on patients in a chronic coma. In Italy, this is not allowed by law and any physician who decided to discontinue life support would be accused of murder.



## What is "brain death" and what is the difference with a coma?

In the case of "brain death", all brain cells have died, leading to an irreversible condition. It would be more appropriate to use the expression "encephalic death" rather than "brain death", since not only the brain but also the cerebellum and the brainstem are dead, meaning that all nerve cells within the skull are dead.

Conversely, in the case of a "coma", the patient's cells are in critical conditions, but they are still vital and send clear signals which can be reliably detected by an EEG: The patient is still alive despite the loss of consciousness and is placed in intensive care. A state of coma may progress to a full recovery; in some cases, patients may have a partial healing with permanent damage (paralysis, slurred speech), and in some other cases there may be a fatal evolution, all cells die and brain death occurs.



#### When does organ donation take place?

Organ donation can only be performed after all possible attempts have been made to save the patient, and only after brain-death has been certified, meaning that the patient's brain will never be able to work again due to a complete destruction of all its cells.

Donation can therefore take place when brain death has been ascertained by the "Commission for the determination of death".



## Can anyone be a donor?

Anyone can donate their organs or just tissue. Even people over 90 years old can donate, for example, their liver, with successful outcomes in the receiving patient.

The health status of the patient prior to death and organ function are carefully evaluated by physicians during the 6-hour observation period before they even suggest that organs be donated and before calling any potential recipients in the regional waiting lists.



## What are the main religious views on organ donation?

They are all in favour of organ donation and transplantation. Leading representatives of the three major monotheistic religions (Christianity, Judaism, Islam) have clearly stated that organ donation is an act of loving one's neighbour, and therefore, for believers, it is a proof of love for their God.



#### Which organs can be transplanted?

Transplantable organs are the kidney, heart, liver, lung, stomach, intestines and pancreas. Some tissues can also be transplanted: corneas, bone segments, cartilage, tendons, vascular segments, heart valves and skin.



## Can donors decide who will receive their organs?

No, they cannot. Organs are given to patients on the waiting list based on the severity of their conditions and the clinical and immunological compatibility between patients waiting for a transplant and donors, so that their precious gift may last as long as possible.



## Who pays for the cost of a transplant? Are there any expenses not covered?

No, in Italy all costs are borne by the National Health System.



## Can organs be sold?

Not in Italy, where transplants from a living donor (kidney or part of the liver) are carried out only between relatives or emotionally related people (eg, between spouses).

The so-called "Samaritan donation" (donating a kidney without knowing the recipient of the organ) is allowed and has been properly regulated since 2010 through a management process established by the Italian National Transplant Centre, after consultation with the Italian National Bioethics Committee and the Italian Board of Health. In Italy, organ removal and transplantation is governed by shared, transparent rules: the origin and destination of each organ is always known; each donation involves many physicians and healthcare professionals who monitor and record every stage of the process; the selection of transplant candidates is governed by clear criteria;

waiting lists ensure transparency and equal opportunities, in relation to clinical conditions, to all patients in the lists. In each Italian region, there is a specialised centre in charge of coordinating all of these activities. The reference transplant centre for Emilia-Romagna is called CRT-ER (Centro riferimento trapianti Emilia-Romagna), located at the S.Orsola-Malpighi Hospital in Bologna. The transplant system is controlled by the Italian National Transplant Centre (CNT). In Italy, organ trade is illegal and the exportation and importation of organs from organ-trading countries are severely punished (Italian Law No. 91 of 1 April 1999).



## Will the donor's family know the identity of the organ recipients?

No, informing the donor's family about the identity of recipients or informing transplant recipients about the identity of their donor is prohibited by law.



#### How do people live after receiving a transplant?

They resume their work, they can travel and play sports again... in short, they return to live a normal life after being seriously ill and often on the verge of death. In most cases, the quality of life of transplant recipients is very good: as an example, we can mention many young women who, even in this region, have become mothers of one or more children after a transplant. In Italy and in Emilia-Romagna, patient and graft survival rates are very high, comparable to the results obtained in the best transplant centres around the world. Also, thanks to medical advances, cases of graft rejection are increasingly rare and more controllable.



### Why should I give consent to be an organ donor?

Sometimes we avoid asking ourselves this question, thinking that organ transplantation is something far from our lives. But we need to know that:

- onating our organs after death means to save human lives
- each of us might need an organ transplant someday.



#### How do I indicate that I want to be a donor?

You can express your willingness to be a donor at all Hospitals in Emilia-Romagna and the Local Health Authorities. The operators will issue a receipt. While ensuring maximum information security, authorised personnel will enter your personal data into a national database located within the Italian National Transplant Centre (CNT), which is connected with all other regional transplant centres. In Emilia-Romagna, this database is queried by the physicians of the reference transplant centre for Emilia-Romagna (CRT-ER) during the observation period of every brain death examination to see whether the patient had expressed willingness to be an organ donor or not. To find out which is the nearest centre to express your will, you can call the Regional Health Service toll free number 800 033 033 (weekdays from 8:30 am to 5:30 pm and Saturdays from 8:30 am to 1:30 pm). But there are also other ways to indicate that you want to be a donor:

- fill in the card attached to this publication and keep it with your personal documents,
- write your statement on a sheet of paper, indicating your personal data (name and surname, date and place of birth, social security number, details of an identity document, e.g. identity card no. ..., issued by the Municipality of ...), date and sign it and keep it with you,
- join AIDO (the Italian association of organ and tissue donors).



### Do I need to tell my family about my choice?

It is always important to inform our families about our choice because, where there is no properly documented will, physicians will only remove the organs if family members do not object (Italian law no. 91/99, section 23). Your will can be changed at any time. When a minor dies, the right to decide goes to the child's parents: if one of the two is against, the organs will not be removed.



## Why are cells taken from living donors?

To perform transplants, but also to carry out thousands of other surgeries, another extraordinary gift is used every day: blood. Thanks to the awareness of citizens and the excellent organisation of a capillary regional network, Emilia-Romagna has always been a national leader in this field. AVIS and FIDAS associations contribute significantly to increasing the number of donors and to the smooth functioning of the regional blood collection system.

Other donations of cells from living donors include bone marrow and cord blood.

For a few years now, Emilia-Romagna has had a regional registry of bone marrow donors which allows healthcare professionals to find donors in a short time and transplant their the bone marrow to patients affected by leukemia. Bone marrow transplant is often the only possible solution. The ADMO Association is committed to supporting this important donation with its initiatives and awareness-raising campaigns.

In addition, at the time of delivery, women can choose to donate their cord blood (which would otherwise be discarded). Cord blood is collected and sent to a dedicated regional bank, which is where checks are carried out and cord blood is stored for any transplantation in compatible children with acute leukemia.



## What are transplant waiting lists?

Patients who need to receive a transplant are put on specific waiting lists to ensure maximum transparency of selection and prioritisation processes before transplant surgeries.

In Emilia-Romagna there has been a single waiting list for kidney transplantation (since 2001), which allows to identify recipients who are the most compatible with the donor.

The region has also activated a single waiting list for liver transplant (since 2004), which gives surgery priority to recipients with the most severe conditions.

Local waiting lists include residents in Emilia-Romagna, but also patients from other Italian regions.

#### THE REGIONAL TRANSPLANT NETWORK

In Emilia-Romagna, all activities involving the donation, removal and transplantation of organs and tissue are coordinated by the reference Transplant Centre for Emilia-Romagna (CRT-ER) at the Sant'Orsola-Malpighi Hospital in Bologna. The CRT-ER coordinates: relations between the ICUs of all hospitals in the region (where donated organs are taken), transplant Centres, tissue and cell banks; activities to ensure the safety of donors and the quality of donated organs; data collection activities; the organisation of waiting lists. It manages the exchange of organs in cooperation with its interregional centre of reference (AIRT - Associazione Interregionale Trapianti), other Italian coordinating agencies (NITp - Nord Italia Transplant program and OCST - Organizzazione Centro Sud Trapianti) and Europe (through the Italian Gate to Europe - IGE), under the constant supervision of the Centro Nazionale Trapianti (CNT), the national transplant centre.

Through proper awareness-raising campaigns, it aims to overcome the mistrust that still adversely affects organ donation and allow each person to make a conscious choice as to whether or not to donate their organs and tissue after death.

The CRT-ER coordinator plays a key role in this complex process: within just a few hours, this physician mobilises at least a hundred resources, including doctors, nurses, biologists, transport workers and laboratory technicians for each donation, in order to successfully perform the transplants and meet the needs of patients on the waiting lists. Another key figure is the local coordinator for donations, a physician who, as part of his/her duties within the hospital, is responsible for the entire organ removal and donation process. The regional transplant network relies on the indispensable collaboration of local institutions and voluntary associations, as well as of patients.

# HOW TO GIVE CONSENT FOR DONATION

- You can express your consent for donation by filling in the card below (to be kept with your personal documents), by joining the AIDO Association (Italian Association for the donation of organs, tissue, cells) or by going to the premises of the Local Health Authorities and Hospitals which are authorised to collect statements of will.
- For information on the nearest centres, the Local Committees for the "A conscious choice" campaign, and, more in general, on donations and transplants in Emilia-Romagna:
  - O Toll-free number of the Regional Health Service **800 033 033** (every working day from 8:30 am to 5:30 pm, Saturdays from 8:30 am to 1:30 pm)
  - www.saluter.it/trapianti
  - http://guidaservizi.saluter.it
- You may also contact:
  - Centro riferimento trapianti dell'Emilia-Romagna (Crt-ER) University Hospital of Bologna, S. Orsola – Malpighi Hospital via Massarenti, 9 - 40138 Bologna Tel. 051 6363665 - 6364708 Fax: 051 6364700 e-mail: airt-crter@aosp.bo.it
  - "A conscious choice" campaign local committees
  - Family Doctor
  - Public Relations Office of the Local Health Authrority
  - Local or provincial AIDO office
    (Italian Association for organ, tissue, cell donation)
  - Regional or local ADMO office (Italian Association of bone marrow donors)



Ristampa aggiornata: maggio 2013

Regione Emilia-Romagna Assessorato politiche per la salute www.saluter.it

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Regione Emilia-Romagna