



Deonú agus Trasphlandú Orgán Éireann Organ Donation Transplant Ireland

# Information for families about organ donation



## **About this guide**

This guide is for family members whose loved one may be suitable to become an organ donor. We understand that this is a very difficult time and hope this guide explains organ donation clearly. If you have any questions, please contact our donor coordinators in Organ Donation Transplant Ireland (ODTI). Our contact details are on p12.

This guide explains how someone becomes an organ donor and what happens:

- before donation
- during donation
- after donation

Every year in Ireland, hundreds of people have their lives saved or dramatically enhanced through receiving the gift of organ donation. This gift is thanks to the incredible generosity of donors and their families who think of others at a time of great loss.

#### How someone becomes an organ donor

Most patients who become organ donors have suffered from an unexpected brain injury. This injury could be due to:

- a physical trauma
- a bleed on the brain
- a stroke
- lack of oxygen from a cardiac arrest

In these cases, the patient will be connected to a ventilator which takes over their breathing and they may require medication to keep their blood pressure at a normal level. They will usually be admitted to an Intensive Care Unit (ICU).

There are two journeys which may result in a patient becoming an organ donor after their death.

- 1. Brain death
- 2. Circulatory death

#### **Brain death**

It sometimes becomes clear to the medical team that the patient's injuries are so severe that they may have already died, even though their heart continues to beat due to the care provided by the ICU. This is known as brain death. It means there is no blood flow or oxygen to the brain. The brain is no longer functioning and there is no hope of recovery.

Two senior doctors (one a consultant) will carry out tests to confirm the diagnosis of brain death. The time of death will be the time when the second set of tests is completed.

#### **Circulatory death**

In some situations, the medical team may conclude that despite what they are doing to save the patient's life, the treatment is not working and that death is unavoidable. The patient cannot recover and cannot survive without the support of a ventilator and/or medication.

In consultation with the family, a decision is made to change the focus of care and accept that death is inevitable. Palliative care is then put in place. This usually includes:

- disconnecting the patient from the ventilator
- removing the breathing tube
- providing measures for a dignified and comfortable death

Decisions about confirming brain death or the decision to begin palliative care are separate from considerations about organ donation. The option of organ donation will only be raised when a family is ready to consider it.

### **Before donation**

#### Referral to ODTI

If you and your family would like to consider organ donation for your loved one, the ICU team will be able to answer your questions. There are nurse specialists that work in ICUs called Organ Donor Nurse Managers (ODNMs) who can meet with you and answer any questions.

You can also ask to speak with one of our team of donor coordinators. They can meet with you and your family to explain the process and how your loved one's donation could save many lives. The donor coordinators are available 24/7 for any queries.

#### What organs and tissues can be donated?

- Heart
- Lungs
- Liver
- Pancreas
- Kidneys
- Heart valves and tissues
- Blood vessels

A number of things happen after you agree to organ donation which we outline on the next page.

#### Life and medical history

- The ICU staff will ask you or your family for information about your loved one's life and medical history.
- The ICU team will then contact our donor coordinators.
   The donor coordinator uses this information when contacting transplant centres to find the right person to receive your loved one's organs.

#### **Blood tests**

The ICU staff will take some blood from your loved one and send these to two laboratories for testing. These tests include matching organ recipients and looking for any viruses present in the blood. The tests take several hours and must be carried out before organ donation can take place.

#### Meeting your donor coordinator

You and your family will meet a donor coordinator. The donor coordinator will explain the organ donation process, answer any questions and help you complete:

- a health and lifestyle questionnaire
- a consent form

The **designated family member** needs to complete these. A designated family member should be the person who knows the most about your loved one.

A full medical and social history is required to ensure the donor coordinator has the necessary information to allow transplant centres make informed decisions on the suitability of organs for transplantation.

#### Keepsakes and follow-up meeting

The donor coordinator will ask if you would like to have a keepsake such as a lock of hair or handprint from your loved one. We will also discuss possible anonymous correspondence between organ recipients and you and your family in the future.

During this meeting, you will be given a contact number where you can contact the donor coordinator or the ODTI team if required.

#### **Coroner and post-mortem (autopsy)**

In some circumstances, a sudden or unexpected death may need to be reported to the coroner. This is regardless of organ donation. The coroner is an official who investigates deaths. The Intensive Care Unit (ICU) team may have discussed this possibility with you. The coroner will decide if your loved one requires a post-mortem.

If a post-mortem is necessary, a family member may need to carry out a formal Garda identification in the ICU.

If the coroner decides that your loved one requires a post-mortem, this may delay receiving your loved one's body from the hospital. However, it should not delay organ donation.

If you have any questions about the coroner or the post-mortem, please ask the ICU staff.

## **During donation**

#### The organ donation operation

Once an organ has been accepted for a transplant patient, a specialist transplant surgical team will be asked to travel to the hospital to carry out the operation. They will go directly to theatre and will have no contact with your family or your loved one until your loved one is moved to theatre for the operation.

The operation can take several hours. It is carried out by a specialist transplant team from the different transplant centres:

- The Mater Hospital for heart and lung transplants
- St Vincent's Hospital for liver and pancreas transplants
- Beaumont Hospital for kidney transplants

Sometimes, if no suitable donor recipient can be identified in Ireland, organs may be offered to transplant centres in the UK and Europe.

During the operation, the surgeons will decide whether the organs are suitable for transplant. If an organ is not suitable for transplant, the organ will stay with your loved one.

The surgeons will only retrieve (take) organs that you have given consent to be donated. Sometimes an organ may later prove unsuitable for donation and if this is the case, we will discuss the options with you during the family meeting. The donor coordinator will be with your loved one throughout the surgery.

After the operation, the transplant team will transport the organ as soon as possible to the hospital where the donor recipient is being prepared for their operation.

## **After donation**

# What happens to my loved one after the operation?

After the operation, your loved one will continue to be cared for by the donor coordinator and the theatre staff with respect and dignity. They will then be moved to the hospital mortuary where their body will remain before being released to the family for the funeral. As previously mentioned, organ donation will not delay a funeral, but a post-mortem may.

#### Does the organ donation affect the funeral?

The funeral should take place as normal. Contact your funeral undertaker who will get in touch with the hospital mortuary and help you and your family with funeral arrangements.

#### Will I be told if the donation was a success?

Yes, the donor coordinator will call you at a suitable time to tell you the outcome of the donation and transplantation unless you have asked not to be contacted. They will answer any questions you have.

# How much information will I receive about any recipient?

Your loved one's organs can be used to save the lives of many recipients, but you will only get limited information. This is to protect the anonymity of the donor, the donor's family and the transplant recipients. Organ donation saves hundreds of lives each year, and to ensure its continued support, it needs to be an anonymous service.

#### Will the recipient know who I am?

No. We do not give the recipient any information that may identify you or your loved one, but they may be told the gender of your loved one.

#### Will the recipient write to me or my family?

Sometimes recipients like to write to the donor's family thanking them for the gift of their new organ. Some recipients write soon after the donation – others take a long time and some may never write. It varies as many struggle with how best to show their appreciation.

At the time of donation, we ask if you would like to receive letters from recipients. We know that agreeing to this on the day of donation can be overwhelming, so please know you can change your mind at any time. If you said yes, these letters will be sent to the donor coordinators to review before you get them.

#### What happens if a letter arrives in ODTI for me?

The donor coordinators will review the letter to make sure the recipients have not given identifiable information. Any letters you receive will never include the recipient's address, telephone number or photograph.

Before you receive your first letter, a donor coordinator will phone you to confirm if you would still like to receive letters. If you agree, the donor coordinators will send any recipient letters to you by registered post.

We will continue to review all letters before sending them to you to ensure they stay anonymous. If you wish to stop receiving letters, please let us know.

#### What if it feels too soon to receive a letter?

We can hold any letters or cards in our office until you feel you are ready to receive them. If it is not something you or your family want anymore, we will not send them to you and they will be kept in ODTI.

#### How can I reply to a recipient?

The ODTI uses the same process to help you send a letter as it does for recipients sending letters. In this way, we ask you not to include information that can identify you or your loved one.

When sending your letter, you need to include two things in the envelope:

**1. Your letter or card in an unsealed envelope.**Please do not seal it as the donor coordinator will review it.

#### 2. A separate piece of paper with:

- your full name
- your loved one's name
- the date of donation

Put both the unsealed envelope and the paper with your information into an addressed envelope and send it to us at:

Donor Coordinators
ODTI
Ground Floor
Bridgewater Business Centre
Conynham Road
Islandbridge
Dublin 8
D08T9NH

The donor coordinators in ODTI will again make sure there is no identifying information within your letter. We will then send it to the transplant centres so they can give it to the recipients.

#### What if I struggle with what to say?

One of our donor coordinators can advise and support you if you need help writing what you want to say. You may like to include the first name of your loved one along with the interests and lifestyle they had.

We ask that you **do not include** the following information in the letters:

- cause of death
- place or date of death
- photographs
- addresses
- phone numbers
- other contact details

# Can I put information about the donation on social media?

Many patient support groups and voluntary organisations use social media to support organ donation. However, we ask you **not to put** sensitive information on social media such as:

- details about your loved one's donation
- recipient letters
- communication from ODTI

## How can I raise awareness about organ donation?

Some families like to raise awareness about organ donation, and you can do this without putting sensitive information on social media. If you would like to raise awareness about organ donation, please get in touch.

#### **Contact us for more information**

If you need assistance or further information on any anything in this guide, please contact us at the ODTI office:







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#### **Mission Statement**

The National Organ Procurement Service works in a compassionate and diligent way to make organ donation possible.

We are committed to increasing awareness and understanding of organ donation among healthcare professionals and the general public.

With respect and sensitivity, we provide individuals and their families with knowledge to make informed decisions about donation.



#### **ODTI Organ Donation and Transplant Ireland**

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