



Brain Death

A SIMPLE EXPLANATION



National Kidney
Foundation®

National Donor
Family Council

This booklet was prepared for you by families who have had a loved one declared brain dead. During that time we found ourselves dealing with questions about what “brain death” really meant. Some of us were still yearning for answers to these questions months, even years, later. We finally found those answers and wanted to share them with you.

Our thoughts are with you.



The diagnosis of brain death is defined as “death based on the absence of all neurologic function.” It may be very difficult to understand. This booklet will help to explain brain death and will provide information to answer some of your questions.



Brain Death

A Simple Explanation

Brain death is death. It is permanent and cannot be reversed.

What does “brain death” mean?

Brain death is a legal definition of death. It is the **complete and irreversible** cessation (stopping) of all brain function. It means that, as a result of severe trauma or injury to the brain, the body’s blood supply to the brain is blocked, the brain dies and it cannot be revived.

Brain death *is* death. It is permanent and cannot be reversed.

What are some of the causes of brain death?

There are many causes of brain death. Head trauma from motor vehicle, all-terrain vehicle and snowmobile accidents, falls, gunshot wounds, hemorrhages in the brain from aneurysms and strokes, medication overdoses, drowning and poisoning, among others, can all cause brain death.

How is it decided that my loved one is brain dead?

A physician conducts the required medical tests to make the diagnosis of brain death. These tests are based on sound and legally accepted medical guidelines that comply with each state's laws.

In some situations, other testing may be needed. You can ask your doctor to explain or show you how brain death was determined for your loved one.

What happens to our loved one while these tests are being done?

Your loved one is placed on a machine that breathes for him or her, called a **ventilator**, because the brain no longer sends signals telling the body to breathe. Special medications to help maintain blood pressure and other body functions may also be given to your loved one.

During the testing for brain death, the ventilator and medications are continued, but they do not interfere with the brain death determination.

*Spinal reflexes,
such as
twitching
or muscle
contractions,
are possible
even though the
brain is dead.*

*Aren't there drugs that can stop
the brain from working and give
a false diagnosis?*

Certain drugs can mask brain function, such as muscle relaxants and sedatives. For a brain death test, these drugs will be cleared from your loved one's system or be present only in low levels. The physician can then accurately measure brain activity. Often, other tests are done to confirm brain death if certain drugs are present.

*If our loved one is really dead,
why is his or her heart still
beating?*

As long as the heart has oxygen, it can continue to work. The ventilator provides enough oxygen to keep the heart beating for several hours. Without artificial help, the heart would stop beating.

Is it possible that our loved one is just in a coma?

No. Brain death is not a coma. A patient in a coma continues to have brain activity and function. When brain death occurs all brain function ceases. Once brain death has occurred, there is no chance of recovery.

Is there anything else that can be done?

Before brain death is declared, everything possible to save your loved one's life is done. After the diagnosis of brain death is made, **there is no chance of recovery**. There is no medical miracle that will reverse brain death.

What happens after my loved one is declared brain dead?

Once the diagnosis of brain death is made, your loved one is pronounced legally dead. This is the time that should appear on the death certificate. The time of death is **not** the time when the ventilator is removed.

*Brain death
is not
a coma.*

*Remember that your loved one
is already legally dead and
removing the ventilator does
not cause death.*

Saying goodbye to a loved one who is brain dead is a very difficult experience. Your loved one may look as if he or she is only sleeping. The ventilator fills the lungs with air. The heart monitors may indicate that the heart is still beating. Your loved one may be warm to the touch and have color in the face. But, in fact, your loved one is dead.

*Does our loved one feel any
pain or suffering after brain death
is declared?*

No. When someone is dead, there is no feeling of pain or suffering.

*After brain death is declared,
what happens next?*

In many cases, brain death is caused by a sudden accident or injury. A health care professional will talk with you about certain decisions you need to make at this time. Among those decisions may be the possibility of organ and/or tissue donation.



SOME FACTS ABOUT BRAIN DEATH AND ORGAN/TISSUE DONATION

*After brain
death is
declared,
organ and
tissue donation
becomes a
possibility.*

What happens if we decide to donate our loved one's organs and/or tissue?

If your family agrees to organ and/or tissue donation, your loved one remains on the ventilator and is supported with fluids and medications to keep blood flowing to the organs and tissue. Tests are performed to determine the medical suitability of organs and tissues for transplantation.

In the meantime, other medical personnel identify potential recipients for the different organs and tissue that can be transplanted. These procedures may take up to 12 hours to arrange. Your loved one's body is then taken into surgery to remove the donated organs or tissue or both. After they are removed, the ventilator is disconnected.

Does our loved one feel any pain when the organs or tissue are removed?

No. Once someone is dead, there is no feeling of pain.

We're not sure if our religion approves of our decision about organ and tissue donation.

Most religions support organ and tissue donation as an unselfish act of charity. However, if you are not sure, check with your religious leader. Many families who have donated the organs or tissue of a loved one feel that they have done something of great and lasting value. Your loved one's "gift of life" stands as a memorial and may reflect what he or she would have wanted.

Will we be told whether our loved one's organs and tissue have been used?

Practices vary regarding the sharing of this information. Most recovery organizations send families a letter telling what organs and tissue were used, which were not used and perhaps a little about

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who received them. However, the names and addresses of the recipients are kept confidential. Donated tissue and corneas may go into an eye or tissue “bank” and be transplanted later, when needed. If you would like information about the procedure or the recipients of your loved one’s organs or tissue, contact your local organ or tissue recovery agency.

Is our family responsible for any of the cost of the donation?

No. All costs related to the donation are the responsibility of the recovery organization or the transplant center. However, hospital expenses occurring before your loved one is declared brain dead are the family’s responsibility.

What will be the outcome of our decision to donate our loved one’s organs and tissue?

Organ and tissue donation is the ultimate act of charity. One person can donate organs and tissue that can help

many patients in need of transplants of different types. The death of a family member is difficult, especially when it occurs unexpectedly and the person was previously healthy. Many families who have donated have said that donation has helped them with their grief.

What if we have more questions?

If you have additional questions, you can speak to your doctor or the coordinator at the local organ or tissue recovery agency that performed the recovery of organs or tissue, or contact the National Donor Family Council of the National Kidney Foundation at 800.622.9010 or by e-mail at donorfamily@kidney.org

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The information contained in this booklet was obtained from an array of health care professionals. We would like to thank the National Donor Family Council along with all the families who participated in our survey and shared their experiences with us.

Thank you.



This brochure is also available in Spanish. Additional resources available through the National Donor Family Council:

- Your Loved One's Gifts:
Understanding Tissue Donation*
- Honoring Each Other's Grief:
Nurturing a Relationship While
Coping with the Death of a Child*
- The Grief Journey: The Death of
a Spouse or Lifetime Companion*
- For Those Who Give and Grieve
(also available in Spanish)*
- For Those Who Give and Grieve
(newsletter)*
- Writing to Transplant Recipients*

To request a complimentary copy of these or other donor family resources, please visit our online store at www.kidney.org/store.



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The National Donor Family Council can provide you with additional support resources. Please contact us at:

National Kidney Foundation
National Donor Family Council
30 East 33rd Street
New York, NY 10016
Phone: 800.622.9010 or 212.889.2210
www.donorfamily.org
E-mail: donorfamily@kidney.org

The Home for Donor Families



The National Donor
Family Council is the largest
national organized group
of donor families in the world.

Notes



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