



Trillium
Gift of Life
Network

Understanding Neurological Determination of Death



Ontario Health
Trillium Gift of Life Network

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It is difficult to imagine a more devastating experience than learning that a loved one has been severely injured and that, despite their beating heart, they have actually died. Words cannot convey the thoughts and feelings you experience at a time when such a sudden and unexpected reality is presented to you.

You may hear and be forced to come to terms with phrases like 'neurologically determined death' or 'brain death'.

How do these medical terms describe the condition of your loved one – and what are you to do with this information?

This booklet seeks to answer some of those questions frequently asked by families. With the help of doctors, nurses, trained counsellors and families who have had first-hand experience, we have written this booklet to help explain what a neurological determination of death means for your loved one and for you.

You might be experiencing emotion and uncertainty that can seem unbearable. We hope that we can provide the information you need to understand neurologically determined death and to answer those questions you might not think to ask in your time of grieving.

Neurological Determination of Death

Neurological Determination of Death – a definition: A diagnosis of death by neurological criteria (sometimes referred to as "brain death") means the brain has permanently lost the capacity for consciousness, and all automated functions in the brainstem (like pupil reaction and blinking reflexes), including the capacity to breathe.

In Canada, people determined to be dead by neurological criteria are legally dead.

- **What causes brain death?**

There are many causes of neurologically determined death. The brain may be badly injured by a stroke or bleeding within the skull. Swelling in the brain can also happen with tumors, infection and severe head trauma. Cardiac arrests caused by a heart problem, drowning, or medication overdoses may also result in severe brain injury. Pressure or swelling from these types of brain injuries prevents enough blood and oxygen from getting to the brain cells. Without proper oxygen and blood supply, the brain begins to die. Once brain cells die there is no way to bring them back to life. When the brain dies, the person can no longer breathe, move, think, or feel. Brain death is permanent, irreversible, and there is no chance of recovery.

- **How is death determined?**

In caring for patients who have serious brain injuries, experienced doctors perform a series of tests to see if the brain is functioning. They check for basic brainstem reflexes, and the ability to be conscious and to breathe. In Canada, these tests are standardized and must be done by two doctors to confirm that they are done correctly. Death is determined when these brainstem functions are gone. When these brainstem functions are gone, they can never come back.

- **What tests are performed to determine if my loved one has died?**

The doctors will examine your loved one. First, they will check to ensure that your loved one doesn't respond to any words or stimulation. Next, they will test to see how structures deep within the brain (the brainstem) are working. This is done by doing tests such as shining a light in their eyes, checking if they can cough and putting cold water in their ears.

The last part of this testing is called the "apnea test". Without the help of mechanical ventilation (breathing machine), the doctors watch very closely to see if your loved one can breathe on their own. They will do blood tests frequently (every five minutes or so) to measure carbon dioxide that builds up in the blood when you don't breathe. Once carbon dioxide reaches a certain level and your loved one shows no sign of breathing, then we know that even the most basic reflexes are gone, and the person can't wake up or breathe on their own again.

Sometimes additional testing, like a scan of the brain to check for blood flow to the brain is also used to help determine death by neurological criteria.

- **I have been told that my loved one is dead but they are still breathing and their heart is beating – doesn't the heart have to stop for death to be pronounced?**

No. Without support from the ventilator, which takes over the function of breathing and supportive medications, the heart is not capable of sustaining itself once brain function is gone. Unfortunately, the function of the brain can't be replaced.

- **Is neurological determination of death different than other kinds of death?**

No. Death occurs when the brain dies. This is why people who have had a cardiac arrest – whose hearts have stopped even for a few minutes – can sometimes be resuscitated and recover; recovery is possible because the brain has not yet died. When the brain has died, there is no possibility of a recovery.

Neurological determined death is death.

- **Couldn't our loved one just be deeply unconscious or in a coma?**

Unfortunately, not. While consciousness is a very important function of the brain, a person in a coma or in a persistent vegetative state continues to have some brain activity even though they are unconscious. People who are determined to be dead by neurologic criteria have lost the ability to ever be conscious again, as well as basic brainstem functions including the ability to breathe.

- **Can anything else be done? Can we wait longer – people say miracles can happen.**

If death of the brain occurs, nothing further can be done that will help the person recover because they have already died.

Using the strict Canadian guidelines developed by experts regarding neurological determination of death, there has never been a recorded case in Canada of a person recovering from a death determined by neurological criteria.

There is no chance of recovery; neurological determination of death is irreversible. A death certificate will be filled out and the Coroner will be called if required.

- **I've heard that people sometimes move or twitch after they've been determined to be brain dead. This doesn't make sense if brain death means that there is no brain function. What is going on?**

Your loved one may exhibit spinal reflexes such as twitching or muscle contractions. Seeing these movements can be confusing and upsetting. Spinal reflexes are caused by electrical impulses that remain in the spinal column. They can occur even though there is no activity in the brain and are in fact a sign that the brain is not controlling the body.

- **What happens after neurological determination of death is confirmed?**

Once the formal testing for neurological determination of death is completed, the team will provide you with a time of death and the death certificate will be completed or, if needed, the coroner will be notified.

The health care team will also speak you to about next steps, and if donation is possible this will include speaking to a Trillium Gift of Life Network Coordinator. The conversation about organ donation needs to occur while your loved one continues to receive oxygen and medications while on the ventilator.

- **Can a "brain-dead" patient be kept on a ventilator indefinitely?**

No. After neurological determination of death is confirmed, if the patient does not have a registered decision to donate as noted from the provincial Ministry of Health database, or if the patient's substitute decision maker for donation does not decide to pursue an opportunity of organ donation, the ventilator will be discontinued.

If organ donation is to proceed, the ventilator and medications will remain in place while testing and matching the organs with potential recipients are completed. The ventilator will be discontinued in the operating room after the recovery of your loved one's organs. It's important to remember that discontinuing the ventilator does not cause death - your loved one has already died.

- **Will we be allowed to spend time with our loved one to say our goodbyes?**

Your loved one's healthcare team will work with you to provide the time and privacy needed to say goodbye and to facilitate any special observances you may wish.

From the time you enter the hospital, you will become part of a team caring for your loved one. Doctors, nurses, educators, donation coordinators, and individuals experienced in bereavement will be there to help explain what is happening, provide you with information concerning your options - or simply to offer an understanding and caring presence as you journey through this difficult time.

- **What if we have more questions?**

Someone will always be available - 24 hours a day, seven days a week to answer your questions related to donation. At the end of this booklet, there is a space to write down the contact number for Trillium Gift of Life Network's Coordinator. Your health care team can also contact the Provincial Resource Centre if you have not yet met with a donation coordinator and you have questions.

Organ and tissue donation is the most precious, unique and altruistic gift a person can give. It is the ultimate act of humanity, making the individuals and families who choose the option genuine heroes of our time.

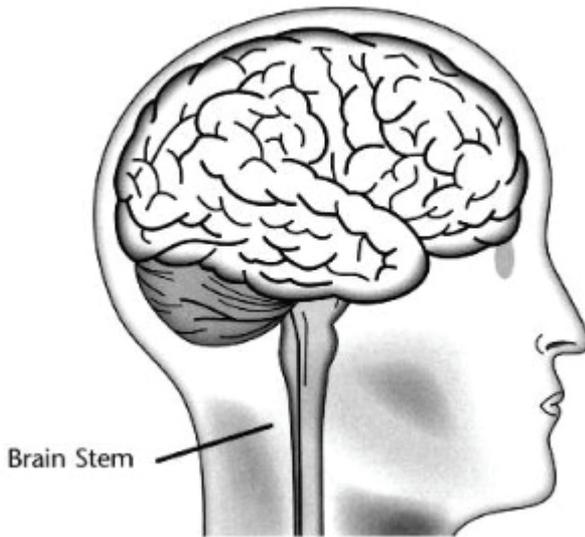
Glossary

- **Apnea** – Cessation of breathing.
- **Brainstem Reflexes** – Reflex actions such as blinking, coughing, gagging, motor and pupillary response to light. The absence of brainstem reflexes indicates the brain is no longer able to send messages to the body to make it work - to breathe and to perform other vital functions.
- **Coma** – A deep, prolonged and sometimes irreversible unconsciousness from which the patient cannot be awakened.
- **Diagnosis** – The process of identifying a disease from its signs and symptoms.
- **Neurologic** – Having to do with the brain and/or other parts of the central nervous system.
- **Persistent Vegetative State** – A persistent loss of brain function that leaves the patient awake but unaware. The condition does not require respiratory or circulatory support (a ventilator).
- **Spinal Reflexes** – Movements that are caused by electrical impulses conducted by, or originating from nerves or spinal cord rather than the brain.
- **Stroke** – A sudden loss of consciousness, sensation, or voluntary motion caused by a lack of oxygen supply to a particular area of the brain.
- **Ventilator** – A machine which mechanically assists a patient's breathing, or takes over this function when they cannot breathe.

Source Material:

- *Severe Brain Injury to Neurological Determination of Death: A Canadian Forum*
April 9 – 11, 2003 Vancouver, British Columbia
Report and Recommendations: Canadian Council for Donation and Transplantation.
- *Brain Death*
Elco F.M. Wijdicks. Published 2001, Lippincott Williams and Wilkins
- *Brain Death – A Simple Explanation*
Booklet published by the National Kidney Foundation, 2002
- *Sharing the Greatest Gift*
A Family Guide to Organ and Tissue Donation. The Sharing Network – Organ and Tissue Donation Services, Springfield, N.J

The Brain



Healthcare Team:

ICU Nurses _____

ICU Doctors _____

Organ and Tissue Donation Coordinator #1

Name: _____

Mobile: _____

TGLN Organ and Tissue Donation Coordinator #2

Name: _____

Mobile: _____

Chaplain/Spiritual care _____

Social Worker _____

Others _____



For more information:

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**Produced by Ontario Health
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*This booklet has been prepared for use by
the families and friends whose loved ones
have suffered a critical brain trauma.*



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