Understanding Neurological Death
Special thanks to Trillium Gift Of Life Network’s Donor Family Advisory Council, whose dedication and commitment never fail to profoundly move us all.
Understanding Neurological Death

It is difficult to imagine a more devastating experience than discovering a loved one has been severely injured and is being examined for signs of life. Mere words cannot convey the feelings of shock and helplessness, and the fear of impending loss we suffer when such a sudden and unexpected reality is presented to us.

It is a time when we may hear and be forced to come to terms with phrases like ‘neurological death’ or ‘brain death’. How do these medical terms describe the condition of our loved one – and what are we to do with this information?

This booklet seeks to help answer those questions. With help from doctors, nurses, trained counsellors and families who have had first-hand experience, we will explain what a neurological determination of death means to your loved one and to you.

We understand that the confusion and uncertainty you might be experiencing in these circumstances can at times seem unbearable. We hope that in these moments of shock and sorrow we can provide the information you need to know about neurological death, and to answer those questions you might not think to ask in your time of intense sorrow and grief.
Neurological Determination of Death

Neurological Determination of Death – a definition: A diagnosis of death by neurological criteria (also referred to as “brain death”) means the brain has permanently lost all function.

As a result of the severe brain injury or trauma your loved one suffered, the accumulation of fluid, blood, or a swelling of the brain cells has caused pressure to build inside the skull, making it increasingly difficult for life-giving blood and oxygen to flow into the brain. Since the bones of the skull create a space only slightly larger than the brain, as the pressure increases, the brain soon has no place to expand. The pressure then builds rapidly to the point that all blood flow to the brain is completely blocked and all brain function ceases.

Without the oxygen the blood delivers, the brain begins to die immediately. Once brain cells die there is no way to bring them back to life; the brain itself dies and no longer functions in any capacity – and never will again. When the brain dies, the person can no longer breathe, move, think or feel. Neurological death is permanent and irreversible and there can be no hope whatsoever of recovery.

Neurological death is death.
How is neurological death caused?

There are many causes of neurological death. A brain hemorrhage or bleed as a result of an aneurysm or stroke is a common cause; others include severe head trauma that may occur in a motor vehicle accident, an injury from a gunshot wound, a severe blow to the head, or brain tumours. Drowning, poisoning, and medication overdoses may also result in neurological death.

How is the diagnosis reached?

A doctor experienced in caring for patients suspected of neurological death will perform a standard series of tests designed to assess the function of the brain. The tests are conducted in such a manner so as to leave no room for error. Once those functions are gone they never come back.

What tests are performed to determine neurological death?

Physical examinations are conducted that detect brainstem reflexes such as gag, cough, physical movement, and the changes in your eyes (pupils) when exposed to light. Apnea testing is carried out, which involves removing the patient from the ventilator (breathing machine) to determine if they will breathe, as well as tests that measure oxygen and carbon dioxide levels in the blood, which determine whether there will be the initiation of breathing.
Sometimes additional testing, like a CAT scan of the brain and/or a brain flow study that checks for the presence or absence of blood flow to the brain is also used to help determine the diagnosis of neurological death.

But my loved one is still breathing and their heart is beating – doesn’t the heart have to be stopped for death to be pronounced?

No. As a result of the emergency treatment your loved one required, they have been placed on a ventilator that takes over the function of breathing for them. As long as oxygen and other intensive care interventions are being supplied, the heart will continue to beat (though for a period of time only), but it is the ventilator and medications, not the heart and lungs that are sustaining the body’s vital functions.

It can be confusing or upsetting to be told that your loved one is dead when you can see the chest rising and falling and see the evidence of the heart beating. But your loved one is not alive or even dying – your loved one is already dead.
Is neurological 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 neurological death has occurred there is no possibility of recovering.

Neurological death is death.

Couldn’t our loved one just be deeply unconscious or in a coma?

Unfortunately not. Coma and neurological death are completely separate and different diagnoses.

With neurological death, medical technology can create the appearance of a living person – though they are dead. A person in a coma or in a persistent vegetative state continues to have some brain activity and would not be treated as neurologically dead.

Neurological death literally means death.
Can anything else be done?

Be assured that everything that could be done to save the life of your loved one has been done. If neurological death has been pronounced, nothing further can be done which will help. There is no chance of recovery; neurological death is not reversible. A death certificate will be filled out and the coroner may be called.

People talk about miracles – do such things happen?

Sadly, no. Using the strict Canadian guidelines developed by experts to determine neurological death, there has never been a recorded case of a person recovering from a determination of neurological death in Canada.

“When death is determined by neurological criteria, it is the same as if the heart had stopped and could not be restarted.” Chief Medical Officer, TGLN
I’ve heard that people sometimes move or twitch after they’ve been diagnosed as 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 activity or reflexes such as twitching or muscle contractions – movements that are understandably confusing and upsetting to observe. Spinal reflexes are caused by electrical impulses that remain in the spinal column. These reflexes can occur even though the brain, and therefore the patient, is dead.

What happens when neurological death is determined?

If the opportunity of organ donation is possible, your loved one may continue to receive oxygen and medications while on the ventilator until the decision is made.

It is at this time that you will be approached with the opportunity to donate your loved one’s organs and/or tissues.
Can a brain dead patient be kept on a ventilator indefinitely?

No. After neurological death has been determined, should the family choose not to accept the opportunity of organ donation, the ventilator will be discontinued. If organ donation is to proceed, the ventilator will be discontinued in the operating room following the recovery of your loved one’s organs. It’s important to remember that discontinuing the ventilator does not cause death - your loved one is already dead.

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 religious or cultural rituals you may have at this time.

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 trained in bereavement counselling will be there to help explain what is happening, provide you with information concerning your decisions – or simply to offer an understanding and caring presence as you journey through this difficult time.

You are not alone.
What if we have more questions?

Someone will always be available – 24 hours a day, seven days a week to answer your questions. Trillium Gift of Life Network’s Provincial Resource Centre is fully staffed with clinical service coordinators trained to help answer your questions. If you have a specific question they cannot answer, they will find the information for you.

Toll Free Information Line: 1 877 363 8456

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 opportunity, genuine heroes of our time.
Glossary

**Aneurysm** – An aneurysm is a dilation of a blood vessel (similar to a balloon) which as it expands has the potential for rupture. Rupture of an aneurysm in the brain causes stroke.

**Apnea** – Cessation of breathing.

**Brain Flow Study** – A test to confirm absence of blood flow or brain activity.

**Brainstem Reflexes** – Reflex actions such as cough, gag, motor and pupillary response to light. The absence of brainstem reflexes indicate the brain is no longer able to send messages to the body to make it work - to breathe and to perform other vital functions. Therefore, brain stem death – neurological death – is death.

**CT or CAT Scan** – A special X-ray technique that uses a computer to incorporate multiple X-ray images into a 2 dimensional cross-sectional image.

**Coma** – A deep, prolonged and sometimes irreversible unconsciousness from which the patient cannot be awakened.

**Determination** – The result of an accurate diagnosis.

**Diagnosis** – The process of identifying a disease from its signs and symptoms.
**Brain Hemorrhage** – A large release of blood from the blood vessels into the brain itself.

**Magnetic Resonance Imaging (MRI)** – A special imaging technique used to show internal structures of the body, particularly soft tissues such as the brain.

**Neurological** – 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, and voluntary motion caused by rupture or obstruction of an artery in 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*
Eelco 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

[Image of a brain diagram]
Healthcare Team:

ICU Nurses ____________________________________________

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ICU Doctors __________________________________________

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Organ and Tissue Donation Coordinator ______________________

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Chaplain _______________________________________________

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Social Worker __________________________________________

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Other _________________________________________________

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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. Their need for information may be greatest when they are at their most vulnerable.

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