



Organ and Tissue Donation: Giving the Gift of Life



Ontario

Trillium Gift of Life Network



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



Organ and Tissue Donation: Giving the Gift of Life

You have just been told that your loved one has died.

Nothing on Earth can remove the pain caused by the loss of a loved one.

In this booklet, Trillium Gift of Life Network seeks to provide the information you may need at a time when the confusion, uncertainty and grief you're experiencing may make it difficult to understand what you're being told.

With help from doctors, nurses, trained counsellors and families who have had first hand experience, we will attempt to explain the course of events that have brought you to this time of contemplation, to offer you information about some of the opportunities that exist and to help you with the decisions you will be making.

From the time you enter the hospital, you become a part of a healthcare team caring for your loved one. Your needs, your wishes and those of your loved one will be the focus of the support you receive. Doctors, nurses, educators, and individuals trained in bereavement counselling, as well as staff from Trillium Gift of Life Network will be available to provide you with the information you need to make a decision about the opportunity to help others through the gift of organ and tissue donation.

Some families in similar circumstances have found that with the opportunity to donate organ and tissue donation, their pain was eased. The generous gift of organ and tissue donation given at the time of a loved one's death may help provide some meaning as families begin to cope with the agony of their loss.

We hope that in this time of shock and sorrow the contents of this booklet will provide the information you need to know and answer those questions you might not think to ask.



Organ and Tissue Donation at End-of-Life

How have we come to this moment – why are we being offered the opportunity to donate organ and tissue?

The opportunity of organ and tissue donation is part of end-of-life care and is introduced when someone has been determined to be dead via neurological criteria ('brain death'). Organ and tissue donation may also be discussed with families if the healthcare team and the family have discussed the withdrawal of life-sustaining treatment at the time when doctors determine medical treatment will not prevent the person from dying.

When a patient has permanently lost all functions of the brain, death is pronounced by neurological criteria. When a patient is pronounced dead by neurological criteria, extensive testing has determined that as a result of severe injury or trauma, irreversible brain swelling has caused pressure to build inside the skull until blood flow has been cut off completely. At that moment, the brain dies and permanently stops functioning with no hope of recovery. The doctor pronounces the patient dead, a death certificate is filled out, and the coroner may be called.

Do people recover from neurological death?

No. When blood flow to the brain has stopped, the brain dies and cannot recover.

Neurological death is death.





Our family hasn't discussed organ and tissue donation – how should we proceed?

The decision to donate is just one of many decisions at end-of-life that you may not have been expecting to be make. Trillium Gift of Life Network is able to access the OHIP database to determine if your loved one had registered a consent decision to donate with their Ontario healthcard and will share this information with you. Whether or not you as a family or your loved one on their own has previously considered organ and tissue donation, a Trillium Gift of Life Network coordinator or designate will work with you to address any questions you have about the decision to donate. Their role is to provide you with information and support at this difficult time. Regardless of the decision you make, the level of support you receive from the healthcare team will not change.

“ I am in continual amazement at how people – even in their saddest moments – think of others. Whether it’s honouring a loved one’s choice to donate their organs, or thinking of the recipients themselves, I am always awed at how people move beyond their own devastation to care about others.”

*Organ and Tissue Donation Coordinator,
Sunnybrook Health Sciences Centre*

Who will help us to make this decision?

If your loved one has not previously made their donation decision known, some people who may assist you in your decision are family members, your faith leader and, should you wish to discuss it with them, the healthcare providers involved in your loved one’s care. A Trillium Gift of Life Network coordinator or designate will discuss with you whether you believe helping others through organ and tissue donation is something that is in keeping with your loved one’s choices during life. They will be available to provide information and answer any questions you might have.

Do ask for any assistance you might need in making the donation decision on behalf of your loved one.



What happens after we decide to make a donation of our loved one's organs and tissues?

Should you agree to organ and tissue donation, your loved one will remain on a ventilator and continue to receive the medications and intravenous fluids required to maintain a supply of blood flow to organs and tissues.

At this point, a Trillium Gift of Life Network coordinator or designate will provide information about details of the process of donation and answer any additional questions you may have. Time will be spent to ensure you are aware of what can be expected.

“My son Andy (organ and tissue donor in 2000) had a very dry sense of humour. He would say: ‘Well mom, you know, organ donation is really just the ultimate recycling program!’ We were just so proud to be able to carry out his wishes. Thirty-five people benefited from Andy’s gift.”

Donor mom and member of Trillium Gift of Life Network’s Donor Family Advisory Council

How is it decided which organs and tissues my loved one can donate?

Tests will be carried out to assess the suitability for transplantation of your loved one's organs and tissues. It is possible that the circumstances surrounding their medical condition or past medical history could have had serious effects on previously healthy organs. Therefore, a variety of simple blood tests can indicate which organs, such as the liver, kidneys, pancreas, and lungs, are suitable for transplantation. To assess the heart, a cardiologist may be consulted to perform an echocardiogram that will reveal the size, structure and motion of the heart. In addition, information will be gathered from your loved one's medical chart and the medical social history questionnaire that is completed with your assistance.

The final decision about suitability for transplantation will be made with a visual examination during the surgery to recover the organs and tissues.



Will our family be involved in this process?

One of the most important areas of organ evaluation will be answered by you - the donor family. You will be asked questions about your loved one's medical history, seeking as much detail as possible. There will also be questions about your loved one's social history, and questions that relate to the possibility of infectious disease that could pose a risk if transferred to organ and tissue recipients. These questions, which are asked in complete privacy and confidence, are standard questions asked about all organ and tissue donations in North America. The questions are similar to those asked prior to a blood donation.

When will my loved one be removed from the ventilator?

In situations of death pronounced by neurological criteria, following the testing, your loved one will be taken into surgery to recover the agreed-upon organs and tissues. When the surgery to recover the organs is complete, the ventilator will be disconnected. If withdrawal of life-sustaining treatment is to occur and your loved one had not met the criteria for neurological death, the ventilator will be removed as part of withdrawal of life-sustaining treatment, prior to recovering organ and tissues.

Will we be able to be there when the ventilator is discontinued?

If the patient has been pronounced by neurological criteria (brain death), the procedure of organ donation does not include being present when the ventilator is removed. If this is a concern that might impact your decision to donate, please talk to the Trillium Gift of Life Network coordinator who can explain why this is important. In circumstances of organ and tissue donation after cardiac death (if your loved one does not meet the criteria for neurological death), there may be some circumstances in which you may be able to be present when the ventilator is removed. Please be assured that everyone involved in your loved one's care will do all they can to ensure that you have the time you need to say goodbye. They understand that, although your loved one is already dead, the time you spend with them before the ventilator is turned off is an extremely important part of the journey in coming to terms with the reality of your loss.



It seems that now my loved one is dead, more is being done for their organs and tissues than was done previously. Why?

This intense period of testing and evaluation may create an appearance of activity around your loved one that was not present prior to the diagnosis of neurological death. Stopping or reversing neurological death due to the severe brain injury your loved one sustained was not possible. The current activity relates only to the narrow window of opportunity for organ recovery, as deterioration of organs and tissues can begin the instant brain death occurs. The healthcare team must work quickly to try to ensure that the gift that you and your loved one have so generously given is able to help as many people as possible.

How long will it take to recover my loved one's organs and tissues?

There are many variables affecting the length of time it may take to complete these procedures, so the period prior to recovery can stretch anywhere from 18 to 48 hours. This begins from the time you are offered the opportunity of organ and tissue donation, to the release of your loved one's body to the funeral home.

The timelines can vary as a result of organ suitability testing, the availability of an operating room for the recovery surgery, surgical recovery teams arriving from across the country, as well as considerations surrounding autopsy in certain circumstances where the coroner is involved.

A Trillium Gift of Life Network coordinator or designate will keep you updated on events as they unfold and will always inform you of unexpected delays.





I worry that donating my loved ones organs and tissues is just too much– they’ve already been through so much.

Please remember that brain death is death and your loved one can feel no pain. Many families and friends of organ donors have described the comfort that participating in organ and tissue donation has provided them. The feeling of creating meaning from tragedy – of saving lives, improving the health and quality of the lives of others, and bringing comfort and joy to individuals and families in desperate need – has been identified as an initial step in healing their terrible loss. Families may feel a deep and lasting connection to their loved one by being able to help fulfill their decision to donate, or by acting on their loved one’s behalf to create a lasting legacy through organ and tissue donation.

Giving the gift of life can be an extremely moving, deeply meaningful process.

“People worry that their loved one has already been through enough – well, the hard part is done – their loved one is gone and they don’t feel any pain. Don’t ever take their wishes away from them! That’s the last good thing you can do for them – it allows them to do good for others.”

Donor mom

If the healthcare team is aware my loved one wanted to be a organ donor, will they receive proper care, or be left to die so organs can be recovered?

The healthcare team’s focus is on saving your loved one’s life. From a medical standpoint, patients must receive aggressive life-saving care in order to be a potential organ donor. Your loved one will receive the care they require, for as long as they require it. No matter how ill potential recipients are, or how much good it is perceived such an act would accomplish, your loved one will receive every possible assistance available.



“I am there for the families who are in the position of potentially donating, and I want them to know what’s going on and to make sure they are comfortable.”

Organ and Tissue Donation Coordinator

How are the recipients chosen?

The sickest people waiting on the list are the first to receive transplants. Other factors that are considered include: blood type, height, weight and length of time waiting for a transplant. For certain organs, such as the kidneys, tissue matching is required. This involves finding the best genetic match between donors and recipients. This is done because we can ensure a perfect or near perfect match thus decreasing the chance of transplant rejection.

Depending on all these factors, as many as 8 people may receive a solid organ transplant and up to 75 others may be able to benefit from live saving or life enhancing transplants from your loved one’s gifts of tissues.

Is there a chance that my loved one’s organs and tissues might not be used – or our specific wishes might not be followed?

Your wishes will be respected in every detail. The Trillium Gift of Life Network coordinator will explain what will occur if any of the agreed upon organs and tissues are not suitable for transplantation. There still may be an opportunity to help others through important transplant research. This will be discussed with you at the time of consent.

In a follow-up conversation you will receive a complete report, and in approximately two to three weeks, you will receive a follow-up letter detailing the outcomes of your donations. This is an opportunity for Trillium Gift of Life Network to formally thank you for your tremendous gift of life and to acknowledge the generous spirit in which it was given.



Will I know who received the gift of my loved one's organs and tissues?

You will also be informed which organs and/or tissues were recovered, and while confidentiality will be maintained on both sides, you will be given some basic facts about the person (or persons) to whom those organs were gifted.

Is there an opportunity to communicate with the recipients?

If a thank you letter is passed on from a transplant recipient, you will be sent the letter, though you will be under no obligation to read it or respond. Whatever your choice, you may need some time to prepare for the intense emotion such a communication may bring.

It is completely your decision.

“As hard as it was to lose our son, the decision to donate his organs was easy. He saved the lives of 4 people and in essence continues to live on. We were and are proud of what he & we were able to do – embrace your gift and I encourage you to write a little note to the surviving family. Those letters help aid in our healing and I am thankful for them.”

Donor mom



Does my religion approve of the donation of organs and tissue?

All major religions support organ and tissue donation. If your religion typically restricts the use of a body after death, consult your religious leader: these requirements may not apply if the donation could save another life.

I am concerned that I won't be given the notice I require to ensure important cultural/religious rituals are carried out before my loved one is removed from the ventilator?

In your discussions with the healthcare team providing care to your loved one, arrangements can be made to address your family's spiritual and cultural needs.

Will the organ recovery surgery prevent us from having a funeral with an open casket?

No. Funeral options are not impacted by the choice of donation. The Trillium Gift of Life Network Coordinator will discuss any special considerations regarding choice of clothing if you plan on a viewing as part of the funeral ceremony.

Is there any expense involved in the testing and surgery that may be incurred by the donor's family?

There are no costs to the family for any of the procedures involved in organ and tissue donation.

Will my loved one's body be treated with respect behind closed doors?

Yes. Know that healthcare providers are extremely sensitive to your loved one's dignity – they fully understand your family's need to know their loved one is being treated with the utmost care and respect.





Organs and Tissues that can be donated for transplantation

There are hundreds of diseases that could affect an organ or other body structures like bone to the point that a transplant is required. We've identified just a few examples for each tissue or organ that can be donated. The following is a brief description of the function of each organ and tissue, and a few examples of why a transplant may be required.

Bowel

A small bowel transplant is an option for people who are suffering from intestinal failure and who are unable to absorb required nutrition through regular digestive processes.

Reasons for transplant:

- Crohn's Disease
- Injured or missing intestine

Heart

The heart is the organ responsible for pumping blood and oxygen throughout the body

Reasons for transplant:

- Cardiomyopathy - enlargement of the heart
- Congestive heart failure - ineffective pumping of the heart

Heart valve transplants are also needed by children who are born with heart birth defects, or for adults whose heart valves have become damaged and impact how well the heart works.



Kidney

The kidneys are the two organs that filter waste from your body through the production of urine. The blood in your body passes through the kidneys about 20 times an hour. Without properly functioning kidneys, patients are required to have the waste removed from their blood by a machine (hemodialysis) three times a week for 3-4 hours at a time.

Reasons for transplant:

- Kidney failure as a result of Diabetes and other illness
- Hypertension (high blood pressure)

Lungs

The lungs are the organs that bring air and blood into close contact so that oxygen can be added to the blood and carbon dioxide removed from it. Without oxygen all cells die.

Reasons for transplant:

- Emphysema
- Cystic Fibrosis

Pancreas

The pancreas is responsible for the regulation of blood sugar levels. When the pancreas fails to work the person becomes diabetic and may need to take insulin. Pancreases are usually transplanted with a kidney.

Two instances where pancreas maybe transplanted alone are:

- A person has already received a kidney transplant from a living donor, but is still in need of a pancreas transplant
- A prior pancreas transplant has failed



Pancreas Islets

If a pancreas is unable to be transplanted as a whole organ, the islets – the parts of the pancreas that create insulin may be collected and transplanted. Pancreas islet transplantation also helps people living with diabetes.

Kidney/Pancreas

Sometimes a double transplant is offered - a combined kidney/pancreas transplant will be considered for treatment of both kidney failure and diabetes. The new kidney filters toxins out of the body, while the new pancreas makes insulin automatically, as the body needs it.

Reasons for transplant:

- Insulin dependent (Type 1) Diabetes
- End stage kidney disease

Liver

The liver is responsible for secreting bile, which aids in digestion, helps process proteins, carbohydrates, and fats. It also stores substances like vitamins. It also helps remove waste from your blood. You cannot survive without your liver and many diseases of the liver are fatal.

Reasons for transplant:

- Tumour
- Hepatitis

“I know nothing about the donor, only that he or she must have been kind, caring, compassionate and generous, something that had to have been learned from you, the family.”

Letter from a grateful liver recipient to a donor family



Bone, Ligaments and Connective Tissue

Donated bone is used in reconstructive surgery to replace the diseased or lost bone. Bone transplantation can prevent amputation and help restore mobility, as well as aid in the repair of physical deformities. Bone is the most common transplanted tissue from deceased donors. In addition, donated connective tissue such as tendons and ligaments are used in surgery to restore the mobility and function of joints. One person donating bone, ligaments and connective tissue can help as many as 75 people.

Reasons for transplant:

- Trauma
- Cancer

Corneas and Ocular Tissue

The cornea is the thin layer of tissue that covers the eye. It focuses light rays on the back of the eye and protects delicate working parts of the eye. Disease, infection, or trauma to the cornea can cause blindness. The gift of renewed sight is made possible through corneal donation and transplantation.

Reasons for transplant:

- Keratoconus
- Fuchs disease



Skin

Skin is considered the body's first line of defense against infection and disease. People who have lost their own skin, primarily burn victims, are very susceptible to many life-threatening infections. The gift of skin donation can protect transplant recipients from these infections until the patient's own skin has time to grow and once again acts as the body's first line of defense.

Reasons for transplant:

- Skin grafts for burn victims

“Because of an eye disease called Keratoconus, I had gone completely blind by the time I was 26. After waiting about 9 months, I was given the most extraordinary gift that one could ever receive – a beautiful healthy cornea that someone had so generously donated. Since then, my vision has been restored and the world is looking just lovely. I will never be able to sufficiently thank the angels that have given me back my life. Because of the donor and his/her family, I now see sunsets, the snow dancing on the tree tops, my mother’s smile...”

Grateful cornea recipient



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:

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A Canadian Forum*

April 9 – 11, 2003 Vancouver, British Columbia

Report and Recommendations: Canadian Council for Donation
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Brain Death

Eelco F.M. Wijdicks

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Booklet published by the National Kidney Foundation, 2002

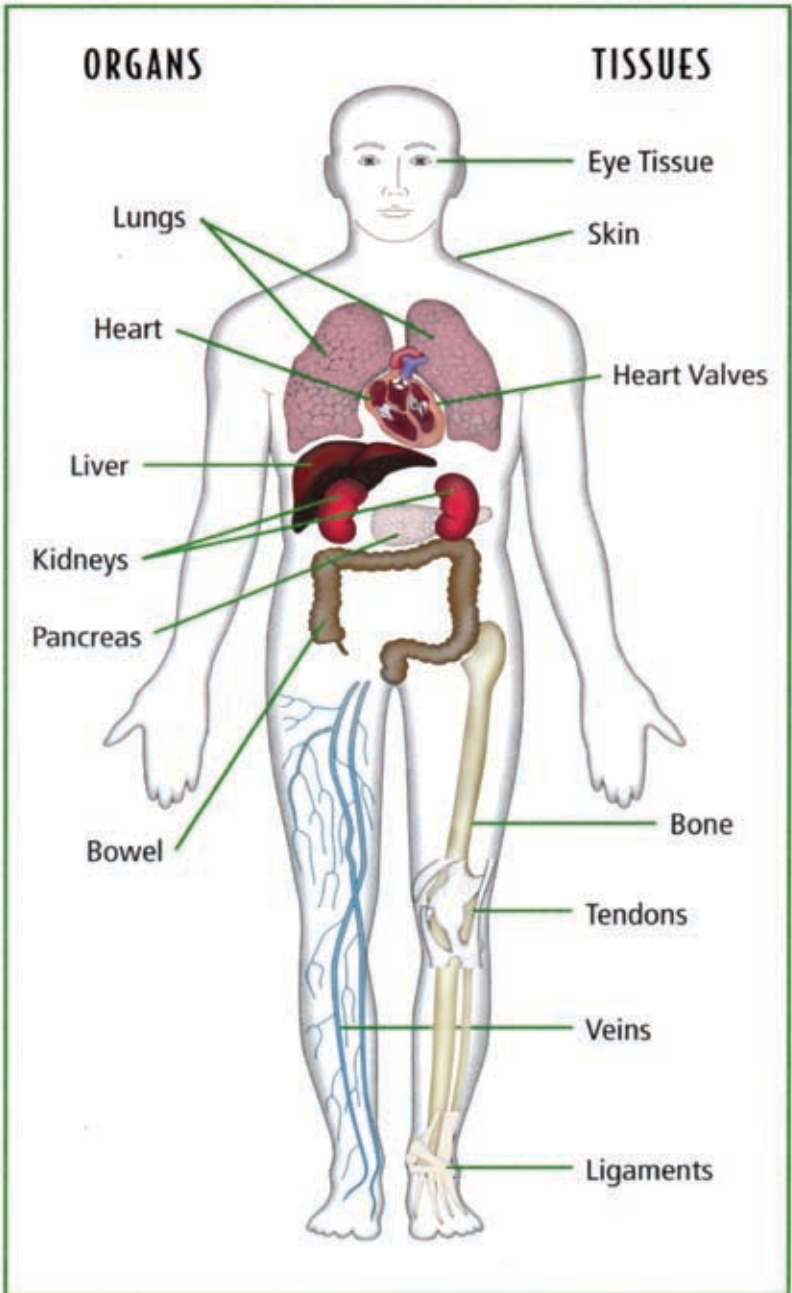
Sharing the Greatest Gift

– *A Family Guide to Organ and Tissue Donation*

The Sharing Network – Organ and Tissue Donation Services,
Springfield, N.J.

The Gift of Tissue Donation

Pamphlet published by LifeNet, Virginia Beach



Healthcare Team:

ICU Nurses _____

ICU Doctors _____

Organ and Tissue Donation Coordinator _____

Chaplain _____

Social Worker _____

Other _____



For more information:

Trillium Gift of Life Network
522 University Avenue, Suite 900
Toronto, ON M5G 1W7

Phone: 416-619-2318

Email: info@giftoflife.on.ca

Toll-Free Information Line:
1-877-363-8456

www.giftoflife.on.ca