

Are there any clinically documented cases where a patient was declared brain dead and later restored to a normal life?

No. When you hear about people who were brain dead and recovered, these people were not actually brain dead. They were in a deep coma or vegetative state with slight brain activity.

How can we deal with our struggle between hope and letting go?

Sometimes we must accept things we cannot change. When brain death is declared, there is no hope, and it is time to let go. False hope can do a great deal of harm and prevents the grieving process that allows for emotional healing.

Are the hospital staff and organ procurement staff adding insult to injury by suggesting and asking for organ/tissue donation at such a time of tragedy and loss?

Organ/tissue transplantation offers life or a better quality of life to another person. It gives the donor family the opportunity to help others at this time of tragedy and loss.

Would we be told what organs were used and to whom they were given?

Generally the names are kept confidential and are not given to the donor or recipient families. By becoming Cadaveric Kidney Donor you can give a new lease of life to many ailing patients.

What is the role of India Renal Foundation in the CKD programme ?

IRF will act as a link between the donor and the recipient. IRF will receive calls from ICUs, hospitals, trauma centers about a patient being brain dead. The volunteers of IRF will go and meet the patient's relatives and try and convince them for CKD.

If the relatives say yes, then IRF volunteers will hand over the matter to the hospital staff who will sign the consent note from the relatives about the donation.

Why an organisation like IRF is needed to do all these things ?

There exists a lot of gap between the donors and the recipients and lot of organs are being wasted, as nobody is interested.

The transplant institute will not play a role since it is perceived as an interested party. The relatives of the brain dead patient do not play a role since mostly they do not know about CKD or are unable to think of such an option at that point of time.

In such an environment, IRF volunteers will tell the patient's relatives about the donation they can give and then handover the matter to the transplant institute.

This will help in increasing CKD rapidly and decrease the number of patients waiting to get transplanted. This will directly increase the amount of transplants taking place in India.

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Cadaveric Kidney Donation Programme

In India . . .

- 1 out of 10,000 people get kidney failure
- About 10 lakh kidney failure patients
- Only 40000 (3-4%) get treated
- 2 year's dialysis cost is equivalent to one transplant cost
- Only about 80 transplant centers
- Only about 3000 kidney transplant / year
- Less than 2% are cadaveric kidney transplant



India Renal Foundation

Exemption u/s. 80G of the Income Tax Act. 1961, granted vide letter no. DIT(E)/80G(5)/1052/01-02 dated 31-10-2002 by Director of Income Tax (Exemptions) Ahmedabad for the period from 14-12-2001 to 31-03-2006.

In India, there are almost 1 million people suffering from End Stage Kidney Disease out of which only 40,000 are getting specific treatment. Only 2500-3000 kidney transplants take place in India every year.

The reasons for very low number of transplants in our country are

- 1) Non-availability of the kidney from living donor
- 2) Less amount of cadaveric kidney donations
- 3) High cost of taking a transplant and maintaining it.

Almost 98% of all kidney transplants occurring in India are live related. A miniscule 1-2% of transplants are cadaveric. There is a limit to how many related transplants that can take place. But cadaveric kidney donation can open new horizons in this area.

What is organ transplantation?

When a disease reaches its end stage, the organ associated with it (which may be kidney, liver, heart etc.) fails. Its function is to be replaced by a similar organ from a different body. The transfer of organ from one person to the other is called organ transplantation.

Why organ donation ?

Many people have diseases wherein only organ replacement is an answer. There are no other treatments or organ replacement is a better treatment than all other available treatments.

Which organs can be donated ?

Organs like kidneys, heart, lungs, eyes, liver, pancreas and intestine can be donated. Tissues like blood, bone and bone marrow can also be donated.

Why kidney donation ?

Once both the kidneys fail, the patient has only two options. Either he has to take dialysis or has to undergo transplantation. The quality of life is better in transplant patient compared to dialysis patients. So kidney donation must be done to improve and prolong the quality of life.

What are the types of kidney transplantation ?

Kidney transplantation can be mainly of three types : (1) Living related : where a living related person donates to his relative e.g. brother to brother or parents to siblings (2) Living unrelated : where a living unrelated (not a

blood relative which includes spouse and other emotionally related people) person donates to the patient (3) Cadaver : where a living person receives a kidney from a brain dead person.

What is Brain Death ? How is it different from death ?

Brain Death can be defined as irreversible loss of all functions of the brain. These patients are not in coma. It is a state where patients cannot regain consciousness, although their heart continues to beat and blood circulation is maintained. A machine called ventilator maintains respiration. The moment the ventilator is switched off, the heart and the circulation of blood stops.

In a normal individual we say a person is dead after the heart stops beating. This is called death. The brain may be alive for some time even after the heart has stopped beating.

How does Brain Death occur ?

1. Due to blockage of an artery leading to the brain or in the brain, heart attack (stoppage of the heart for a period of time), bleeding in the brain.
2. Due to a head injury (a blow to the head)
3. Due to destruction of brain tissue and swelling of the brain.
4. Due to the ballooning of a blood vessel supplying the brain. It can cut off blood supply or rupture.
5. Due to brain tumors which can destroy brain tissue and increase pressure within the brain.

When any of the above occurs, they cause swelling of the brain. Because the brain is enclosed in the skull, it does not have room to swell, thus pressure within the skull increases. This can stop blood flow to the brain killing brain cells.

How is Brain Death determined ?

Team of independent doctors who are not involved with the patient's treatment decides it. These doctors conduct a series of tests to confirm that the patient is truly 'Brain Dead'.

What is Cadaveric Kidney donation (CKD) ?

When a person is brain dead, the body is called a cadaver. If kidneys are donated from this body it is called Cadaveric Kidney Donation.

Who can donate organs ?

If a person's age is between 18 to 55 years, his/her organs can be donated.

How many people can be helped from one cadaver?

At least 2 people can get one kidney each. The relatives can also donate other organs and help as many as 8 people suffering from various diseases.

Who are the people involved in the process of CKD ?

The patient's relatives are the most important people who are involved. The next being transplant coordinators, who try and convince the patient's relatives to make the donation. Specialist doctors like Nephrologists, Urologists, Neurologists are involved in the whole process.

Does donor family need to pay for anything ?

No. You and your family need not pay anything for organ retrieval.

Does one's family gain monetarily out of the kidney donation ?

No.

Does kidney donation leave the body deformed ?

No. The normal clothes we wear cover the incisions for organ removal. Kidney donation does not interfere with the customary funeral.

Which law permits the CKD in India ?

The HOTA, Human Organs Transplantation Act, 1994 permits the CKD.

Is selling of kidneys permissible ?

HOTA strictly prohibits the sale of kidneys.

Will my kidneys be taken away without any of my family members consent ?

Even if you have consented to organ donation before your death, by law, the consent of the next-of-kin or relatives has to be taken before removal of any organ.

Is it ok religiously to donate kidneys and other organs ?

In the entire world, such type of donation is considered invaluable. You can live even after your death through your organs. Every religion and religious head has promoted this noble activity.