

Kozhikode District Panchayat Initiative



SNEHASPASHAM

Kidney Patients Welfare Society
District Panchayath, Kozhikode
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JEEVAL DANAM
*Donate Life by
Donating Organ*

Snehasparsham Kidney Patient's Welfare Society

TO DO LIST FOR DECEASED DONOR ORGAN DONATION:

STEP WISE APPROACH

What to do if your patient is apparently brain dead ?

Deceased donor organ donation usually happens on an emergent basis. . Only after confirmation of brain death we can discuss with relatives regarding the option of deceased-donor organ donation. The generous humane act of the donor family should be respected and appreciated . Communication with donor family and clarification of any of their concerns is of utmost importance. Deceased donor organ donation and subsequent transplantation involves coordination of different departments on an emergent basis. Going through the process through the following steps would ensure smooth execution of the whole process in a timely and systematic manner.

1) Initial diagnosis of brain-death: considering the overall clinical profile (with supportive imaging) if the patient is apparently brain - dead , we can informally discuss the options with the family. Doing and documenting an "Apnea test" before discussing with the relatives would be ideal. If the relatives are willing for organ donation , we have to officially confirm brain-death.

2) Confirmation of brain-death: One neurologist/neurosurgeon either from your hospital or outside (either should be from Government approved panel), physician in charge of patient, registered medical practitioner from outside hospital from government approved panel and hospital administrator should be available at this stage of declaration of brain-death. Make sure an Apnea test is done and ABGA print-outs are recorded and displayed.

(Note: If you don't get a doctor of panel we can resort to a Neurophysician/Neurosurgeon outside the panel or any Physician or any Intensivist subject to KNOS approval (Telephonic permission from nodal officer)

3) Consent: We can discuss in detail regarding all aspects of organ-donation at this stage. Get consent from the nearest relative of deceased donor in official form (Form 6 for adults and Form 9 for minors) . Make sure the organs that family wants to donate is properly discussed and mentioned.

4) Informing state authorities: After attaining family consent - inform nodal officer of KNOS (see contact details below) . Nodal officer's office would be coordinating organ procurement and allocation.(Informing Nodal officer can be done at any stage).

5) Once the family consents, we have a gap of 6 hours till second brain-death confirmation. During this gap we have to

i) Donor work up: Confirm blood group and do serology (HIV, HCV, HBsAg) . Other investigations pertaining to organ donation has to be done subsequently -LFT, RFT, CBC, Urine R/E, USG Abdomen + KUB, Na and K. 2D echo is to be done if heart donation is contemplated.

ii)) Inform Police /Forensic dept (If MLC)

iii) If the hospital is not a transplant center, to get official permission for doing the organ procurement surgery , the administrator has to apply for an ADHOC permission which has been simplified by emailing scanned copy of the duly filled ADHOC Application form (see attachment) to KNOS (email id: principalmct@gmail.com).

iv)) Inform local Ophthalmology hospital in charge of eye donation. KNOS is not directly involved with its procurement and allocation.

v) Collect blood for cross match in Green topped heparinised test tubes (12 ml)

vi) Make sure police intimation and formalities are in place by the time of second brain-death certification. We have to avoid unnecessary delays after second brain-death certification and proceed with organ procurement.

6) Second brain-death declaration and certification to be done with all 4 members of expert panel together (Treating physician, Hospital administrator, Neurologist/Neurosurgeon, Outside doctor from Panel/as per exception mentioned above)

7) Family given an opportunity to see the deceased donor for a final time before patient leaves for OT.

8) Confirm that Police inquest (police from site of accident has to come) formality is done before patient (deceased donor) goes to Operating room.

9) In Operation theater - withdrawal of life support , organ retrieval and subsequent clinical death of donor occurs. No delay in handling over the body to relatives. If it is a medico legal case - arrangements for post mortem without delay has to be arranged.

10) All expenses towards management of deceased donor after consent (excluding transportation charges) not to be borne by the donor family.

CARING OF DONOR FAMILY

* Donor family's sentiments to be protected and respected at all times.

* Donor family should be given proper accommodation in the hospital or hospital premises as sometimes delays can happen . As family is going through a phase of grief , any step to make their life comfortable is invaluable.

* A transplant coordinator should be physically present along with donor family till the body is handed over.

* Neither the identities of the donor nor that of the recipient to be revealed to the media without respective permissions

Certificates to be issued and made available at the time of handing over body :

- a) Photocopy of consent given by relatives (Form 6 and Form 9)
- b) Photocopy of brain-death certificate (Form 8)
- c) Death certificate (Hospital issued)
- d) Organ retrieval certificate: Create one citing the organs retrieved for organ donation (Hospital issued)

Important phone numbers to contact for help and support

Dr Noble Gracious (Nodal officer , KNOS) : 9446390313

Mr Sreeprasad K (Transplant coordinator, Kozhikode District Panchayat) :9847891776

Ms Shahna Beena (Transplant coordinator , MIMS, Calicut) : 9846146259

Dr Sreelatha (Professor and HOD Nephrology, Medical college, Calicut): 9446338109

Dr Feroz Aziz (Nephrologist) : 9446519919

Attachments :

- 1) Brain death certification form (GO on brain death certification & Government issued- Form 8)
- 2) How to do Apnea test? (Government issued)
- 3) Consent form (Government issued - Form 6 for adults, Form- 9 for minors)
- 4) Latest guideline by American Academy of Neurology
- 5) Form for ADHOC permission for organ retrieval by a center not authorized to do transplantation (Government issued)
- 6) Format of organ retrieval certificate

FREQUENTLY ASKED QUESTIONS ABOUT DECEASED DONOR

ORGAN DONATION & TRANSPLANTATION

ORGAN TRANSPLANTATION

Q. Can a person survive if organs fail?

A. Vital organs like heart, kidney and liver are important in sustaining life. Irreversible and advanced failure of these organs due to diseases from various causes can cause death. Failure of some organs (eg:pancreas, eye, intestine) may not be life threatening but can result in significant ill health and morbidity.

Q. Which all organs can be transplanted?

A. Cornea, Kidney, liver, heart and pancreas are organs commonly transplanted. Transplantation of intestines and limbs can also be done in specialized centers. Though not a solid organ, bone marrow transplantation can be done from a living donor.

Q. Why do we say that there is a shortage of organs to help patients in organ failure?

A. Kidney and liver are the only solid organs that can be transplanted from a living donor. To find a healthy compatible living donor is not easy and the number of patients in need is overwhelming. Heart, pancreas and cornea cannot be taken from a living donor. Hence there is real shortage of organs to transplant relative the needy population. A reliable deceased donor program is the only viable solution to this problem.

ORGAN DONATION

Q. Why should we advocate brain death organ donation ?

A. Please see the response to the previous question

Q. How many organs can be transplanted from a deceased donor ?

A. At least seven organs can be transplanted from a deceased donor. Two kidneys, two corneas , one liver, one heart and one pancreas. As mentioned above intestine transplantation and bone graft could also be done.

Q. How will I benefit if my kin donates an organ?

A. Donating an organ is considered equal to donating a life. In many instances a person with organ failure will die if not transplanted soon enough. Saving and protecting a fellow human being's life whenever we can, is one of our fundamental responsibilities. By helping a needy

person with organ transplantation you are not just giving someone a gift of life but also are improving the lives and destinies of an entire family and perhaps even generations to come. The benefit on offer is clearly beyond anything that money can buy. There are no monetary incentives at any level to any person involved in brain death organ donation.

Q. Who decides on which all organs could be donated ?

A. It is the prerogative of the donor family to decide on which all organs are to be donated. The family can consent for the donation of one organ or multiple organs.

BRAIN DEATH AND ORGAN DONATION

Q. Do the terms "Brain death donor", "Cadaver donor" and "Deceased donor" mean the same?

A. Yes, all the three terms are conceptually the same. The most accepted and suitable terminology is "deceased donor". The term "cadaver donor" should be avoided as cadaver denotes a dead body.

Q. What is brain death?

A. Brain death happens in patients who had the misfortune of suffering from non treatable, irreversible brain damage due to injury or disease. Brain dead patients would not have any meaningful function of the brain and would not be able to breathe by self, but they would have a functioning heart which would be pumping blood to all organs. Their "life" would be supported on ventilator. A brain dead patient's heart would stop eventually within 2-3 days of him/her becoming brain-dead and the patient would be pronounced clinically dead.

Q. How common is brain - death ? In what situation does brain death usually happen ?

A. Statistics have shown that in 5% of patients clinical death happens subsequent to brain death. Brain death usually happens in the setting of traumatic head injuries or Cerebrovascular accidents (like intracranial hemorrhage or infarcts). Rarely, infection of brain can cause brain death.

Q. Will the agenda of organ donation influence the treatment offered?

A. Whether organs have been pledged for donation or not, there will be no difference in the medical treatment, care and support given. No doctor or facility will deviate from this principle. Organ donation can only happen after brain death has been declared and certified by physicians (expert panel) who are not connected in any way with organ retrieval or the transplant teams.

Q. How is that "Brain-death" state facilitate organ donation ?

A. The window of 2-3 days between brain death and clinical death gives an opportunity for the bereaved family to donate vital organs from a humanitarian standpoint. All transplantable organs can be procured for transplantation from a brain dead donor. Once brain dead, there are only two reasons to maintain life on life support system like ventilator, first being to

consider organ donation and secondly for allowing time for the bereaved family to arrange for last rites of the patient.

Q. Is Brain-death reversible ?

A. Brain death is not reversible. Please see previous question for details.

Q. Are brain death and coma the same?

A. Brain death and coma are not the same. Some coma states are reversible where as brain-death is always irreversible. Brain death has been clearly defined. There are objective tests and unequivocal criteria for its confirmation.

Q. Is the brain death accepted globally ? Has Indian government approved this ?

A. Medical community had accepted the entity of brain death across the globe in 1960s. It was in 1968 that the Harvard Medical School came up with objective criteria to diagnose brain death. Through the years some clarification and amendments have been done. The existing guidelines have been in place for almost two decades though some updates have been done. Indian government has accepted brain-death for organ donation in 1994. (Transplantation of Human Organs Act (THO) 8th July 1994.

Q. Who is supervising the organ donation program ?

A. Brain death as a death criteria was accepted by Indian Parliament in 1994. All states have transplant authorities responsible for transplant activities. In Kerala there is a dedicated government body to supervise the Brain- dead organ donation program called Mrithasanjeevani. Any organ donation in Kerala takes place under their permission and supervision only. It comprises of government officials , doctors and responsible individuals from different sections of the society. In Malabar region Kozhikode Jilla panchayat has been involved in mobilizing resources to facilitate deceased donor program. Jilla panchayat has a special program called to Jeevaldanam and a dedicated Transplant coordinator to facilitate this program.

Q. Is diagnosis of brain death difficult? Who establishes (certifies) the diagnosis of brain death?

A. Brain death is mainly a clinical diagnosis supported by some objective tests. No expensive tests are needed to diagnose brain-death.

The panel consists of:

- a) Doctor in charge of the hospital (medical superintendent)
- b) Doctor nominated from a panel of Doctors appointed by the Appropriate authority
- c) Neurologist/neurosurgeon nominated from a panel appointed by the appropriate authority
- d) Doctor treating the patient.

These four doctors carry out the tests together to certify brain death.

Q. Is brain death declaration different even if we are not doing organ donation?

A. Brain death declaration is as per criteria and it is same and standardized irrespective of organ donation.

"LEGAL" AND "ETHICAL" ISSUES OF DECEASED DONOR ORGAN TRANSPLANTATION

Q. Can organ donation cause procedural delay?

A. Confirmatory tests for brain death have to be done twice with an interval of six hours between the tests. Once consent for donation has been obtained, coordinating the process of organ retrieval takes time. Organ retrieval from deceased donors involves many hospitals and transplant teams to ensure that the organs donated match as perfectly as possible with the recipient. If it is a medico-legal case, a post-mortem has to be performed and this involves both the police and Forensic Medicine departments.

Q. Who can legally give consent for organ donation when a patient is brain-dead ?

A. A person legally in possession of the deceased person can sign the consent form. This is usually done by a parent, spouse, son/daughter or brother/sister. By signing a consent form the family says that they do not have any objection to the removal of organs from the body of their loved one. It is a legal document. This form is kept with the hospital.

Q. How is a potential recipient identified? If my organs are donated, who decides who receives them? Can the donor family get involved in recipient selection process?

A. The patients who have organ failure and want a transplant are listed in a waitlist according to their seniority based on the duration of illness and other clinical criteria depending on the organ involved. The waitlist and organ allocation is supervised by the supervising state authority.

The family of donor can definitely recommend a relative or acquaintance with organ failure as potential recipient, but his or her candidacy can be accepted based on medical fitness of the patient and ideally should be enlisted in the waitlist.

Q. Is commercial dealing of organs forbidden by law?

A. Report of submission of false records and other misdemeanors should be sent to the Appropriate Authority in the State Government's Department of Health. The Appropriate Authority can file a criminal case against the party.

A hospital, authorization committee, or a person can approach the appropriate authority with the information. The 2011 Amendment of the THO Act gives the following offenses:

Offence (THO Act 2011 Amendment)	Imprisonment	Fine
Removal of organs without authority	10 years	Rs. 20 Lakh
Removal of organs without authority - Penalty for RMP	1st offence: de-registration for 3 years	2nd offence: permanent de-registration
Commercial dealing in organs, falsification of documents	5 – 10 years	Rs. 20 Lakh – 1 crore
Any violation of THOA	5 years	Rs. 20 Lakh

MISCONCEPTIONS ABOUT DECEASED DONOR ORGAN DONATION

Q. Does anyone get any monetary benefit?

A. There is no monetary benefit at any level to any person involved in brain death organ donation. This is an act of the society for the society.

Q. Will I have to spend any money if I agree for my kin's organ donation?

A. The relatives of donating patient's family would not have to pay anything with regard to organ donation. Any expenses after the family consents for organ donation would be borne by hospitals, recipient families and government.

Q. Does organ donation surgery / procedure cause any disfigurement to patient's body?

A. Not at all. All organs are procured by standard surgical techniques worldwide. Eye donation also does not produce any disfigurement.

Q. Is my religion against organ donation ?

A. Virtually no major religion is against organ donation. Two fundamental principles on which all religious thoughts converge are - monetary benefit should not be the motive or end result of organ donation program and the deserving patients should get the benefit of the whole exercise.

RELIGIONS AND ORGAN DONATION

HINDUISM: believe in transmigration of the soul and reincarnation, whereby the deeds of an individual in this life will eventually determine its fate in the next. An important tenet of Hinduism is to help those who are suffering, and *Daan*, or selfless giving, ranks third among its *Niyamas* (virtuous acts). Physical integrity of the dead body is not seen as crucial to reincarnation of the soul.

ISLAM : altruism is also an important principle of Islam, and saving a life is placed very highly in the Qur'an—'Whosoever saves the life of one person it would be as if he saved the life of all mankind' (Holy Quran ; chapter 5:32). In Kingdom of Saudi Arabia - 25% of the transplantation is from brain-dead donors.

CHRISTIANITY: Most Anglican, Catholic and Protestant scholars seem to agree that organ donation is an act of selflessness and endorse transplantation. Popes Benedict XVI and John Paul II has publicly endorsed organ donation.

JUDAISM: Saving a life is a fundamental value in Judaism (*pikuach nefesh*). In fact, Jewish law demands that one should violate almost all other commandments to save a life (except for the prohibitions of murder, idolatry and illicit sexual relations).

SIKHISM: Sikhs believe in life after death, and a continuous cycle of rebirth. In Sikhism, the physical body is not crucial to the cycle of rebirth, as the soul of a person is eternal while the body is simply flesh.

BUDHISM: Giving is the greatest of Buddhist virtues. The Buddha in a previous life gave his body to a starving tigress who could not feed her cubs. There are many such Jataka tales some in which he even gave his eyes to someone who wanted them.

What we can do

- 1) Spread the awareness among all sections of the society. There would be situations or gatherings where you as an individual can exert your influence and create awareness about organ donation and try to utilize those opportunities for this noble purpose .
- 2) Volunteer to be a registered organ donor by signing a donor card online(link-<http://knos.org.in/donorcard.asp>). You can also register as a donor with your identification number (Adhaar card) through Snehasparsham office.
- 3) If you need any information about deceased donor organ donation -please contact Snehasparsham through our contact information given below. We can provide all technical help in facilitating all aspects of deceased donor organ donation and transplantation.
- 4) If you need to conduct an awareness class at any forum - please contact Snehasparsham through contact details mentioned below. We can conduct onsite classes as per your requirement and target audience.
- 5) Appreciate and acknowledge any donor family member that we come across.
- 6) Any philanthropic help towards this program is welcome.

CONTACT DETAILS OF JEEVALDANAM **(Project by Kozhikode Jilla Panchayat)**

Jilla Panchayat.
Calicut , Pin 673020
Kerala,India Ph: 0495-3104994
email: snehasparshamkidney@gmail.com
jeevaldanam@gmail.com

Important Contact phone numbers for deceased donor transplantation:

Mr Sreeprasad (Transplant coordinator Kozhikode, Jilla Panchayat) : 9847891776 / 04953104994
Dr Sreelatha (Professor and HOD, Nephrology , MCH-CLT) : 9446338109
Dr Feroz Aziz(Consultant Nephrologist , Calicut) : 9446519919
Dr Benil Hafeeqe (Consultant Nephrologist , Calicut) : 9846090874
Shahana P A (Transplant coordinator) : 9846146259
Toll Free Organ Donation Helpline (KNOS) : 1800 - 4193737

Sources of information:

Kerala Network for Organ Sharing : www.knos.org.in
Jeevaldanam : www.snehasparsham.com/jeevaldanam
Kidney federation of India (NGO) : www.kidneyfederationofindia.org