

# **FAQs**

## **I. Organ & Tissues Donation**

### **1. What is an Organ?**

An organ is a part of the body that performs a specific function: like your Heart, Lungs, Kidney, Liver etc.

### **2. What are the Organs that can be donated?**

The organs that can be donated are: Liver, Kidney, Pancreas, Heart, Lung, Intestine.

### **3. What is Tissue?**

Tissue means a group of cells performing a particular function in the human body. Examples would be bone, skin, cornea of the eye, heart valve, blood vessels, nerves & tendon etc.

### **4. What are the tissues that can be donated?**

The tissues that can be donated are: Cornea, Bone, Skin, Heart Valve, blood vessels, nerves & tendon etc.

### **5. What is Organ Donation?**

Organ Donation is the gift of an organ to a person with end stage organ disease & who needs a transplant.

### **6. What are the different types of Organ Donation?**

There are two types of organ donation:

i) Living Donor Organ Donation: A person during his life can donate one kidney (the other kidney is capable of maintaining the body functions adequately for the donor), a portion of pancreas (half of the pancreas is adequate for sustaining pancreatic functions) & a part of the liver (the segments of liver will regenerate after a period of time in both recipient & donor).

ii) Deceased Donor Organ Donation: A person can donate multiple organs & tissues after (brain-stem/ cardiac) death. His/ her organ continues to live in another person's body.

### **7. Is there any age limit for Organ Donation?**

Age limit for Organ Donation varies, depending upon whether it is living donation or cadaver donation; for example, in living donation, person should be above 18 years of age, & for most of the organs, the deciding factor is the person's physical condition & not the age. Specialist healthcare professionals decide which organs are suitable for transplantation, depending on a case-to-case basis. Organs & tissue from people in their 70s & 80s have been transplanted successfully all over the world. In the case of tissues & eyes, age usually does not matter.

A deceased donor can generally donate the Organs & Tissues with the age limit of:

Kidneys, liver: up to 70 years of age  
Heart, lungs: up to 50 years of age  
Pancreas, Intestine: up to 60-65 years of age

Corneas, skin: up to 100 years of age  
Heart valves: up to 50 years of age  
Bone: up to 70 years of age

## **8. Who can be a Donor?**

Living Donor: Any person not less than 18 years of age, who voluntarily authorizes the removal of any of his organ &/ or tissue, during his or her lifetime, as per prevalent medical practices for therapeutic purposes.

Deceased Donor: Anyone, regardless of age, race or gender can become an organ & tissue donor after his or her Death (Brainstem/ Cardiac). Consent of near relative or a person in lawful possession of the dead body is required. If the deceased donor is under the age of 18 years, then the consent required from either parent or any near relative authorized by the parents is essential. Medical suitability for donation is determined at the time of death.

## **9. How can I be a Donor? What is the process to take Donor Pledge?**

You can be a donor by expressing your wish in the authorized organ and tissue donation form (Form-7 As per THOA). You may pledge to donate your organs by signing up with our website [www.notto.nic.in](http://www.notto.nic.in) and register yourself as donor or for offline registration you may download Form 7 from our website. You are requested to fill the form 7 and send signed copy to SOTTO – U. P. or NOTTO at the below mentioned address:

### **SOTTO – U. P.**

Department of Hospital Administration  
4<sup>th</sup> Floor, Central Library Complex  
Sanjay Gandhi Post Graduate Institute of Medical Sciences  
Raebareli Road, Lucknow, U. P. – 226014

### **NOTTO**

4<sup>th</sup> Floor, NIOP Building  
Safdarjung Hospital Campus  
New Delhi – 110029

## **10. Do I need to carry my donor card always?**

Yes, it will be helpful for the health professionals and your family.

## **11. Do I need to register my pledge with more than one Organization?**

No, if you have already pledged with one Organisation & received a Donor Card, you need not register with any other organisation.

## **12. Can a person, without a family, register for pledge?**

Yes, you can pledge, but you need to preferably inform the person closest to you in life, a friend of long standing or a close colleague, about your decision of pledging. To fulfil your donation wishes, healthcare professionals will need to speak to someone else at the time of your death for the consent.

### **13. What is the benefit to my family or me after donation of organs?**

Donation of an organ or tissue provides an unparalleled opportunity to give someone a second chance of life. Your donation is not only giving impact to the life of one person or family, but it is of overall help for the society as a whole.

### **14. If I had pledged before, can I change my mind to un – pledge?**

Yes, you can un – pledge by making a call to the your SOTTO/ NOTTO office or write or visit the SOTTO/ NOTTO website(s) [www.sottoupdoha.in](http://www.sottoupdoha.in) or [www.notto.nic.in](http://www.notto.nic.in) & avail of the un-pledge option by logging into your account. Also, let your family know that you have changed your mind regarding organ donation pledge.

### **15. Are there any religious objections to donate Organs & Tissues?**

No, none of our major religions object to donate organs and tissues, rather they all are promoting and supporting this noble cause. If you have any doubts, you may discuss with your spiritual or religious leader or advisor.

### **16. How many patients need organ transplant in India on an average?**

In India, there is a growing need of Organ & tissue transplant due to large number of organ failures. As there is no organized data available for the required organs, the numbers are only estimates. Every year, following number of persons needs organ/ tissue transplant (as per organ specified):

<b>Name of the Organ/ Tissue</b>	<b>Estimated number of organs required per annum in India</b>
Kidney	~2,50,000
Liver	~80,000
Heart	~50,000
Cornea	~1,00,000

### **17. The people who have pledged for organ Donation in life, will they definitely become organ donors?**

No, only a few people die in such circumstances where they are able to donate their organs. That is the reason we need people to take pledge for Organ Donation & register themselves as potential Donor.

### **18. Are donors screened to identify if they have a transmissible disease?**

Yes, Blood is taken from all potential donors & tested to rule out transmissible diseases & viruses such as HIV & Hepatitis. The family of the potential donor is made aware that this procedure is required.

### **19. Can I be a donor if I have an existing medical condition?**

Yes, in most circumstances you can be a donor. Having a medical condition does not necessarily prevent a person from becoming an organ/ tissue donor. The decision about whether some or all organs/ tissues are suitable for transplant is made by a healthcare professional, taking into account your medical history.

In very rare cases, the organs of donors with HIV or Hepatitis – C have been used to help others with the same conditions. This is only ever carried out when both parties have the same medical condition. All donors have rigorous checks to guard against infection.

### **20. Can I be an organ donor, if I have been rejected to donate blood?**

Yes, the decision about whether some or all organs/ tissues are suitable for transplant is always made by a specialist, taking into account your medical history. There may be specific reasons as to why it has not been possible to donate blood, such as having anaemia or you had a blood transfusion or had Hepatitis in the past or there may be reasons why you could not donate blood because of your health at the time – sometimes a simple thing like a cold or medication that you are taking can prevent you from donating blood.

### **21. How does whole body donation differ from organ donation?**

Organ donation for therapeutic purposes is covered under the Transplantation of Human Organs Act (THOA 1994) & subsequent amendments. Whole body donation is covered by the Anatomy Act 1984.

Organ & Tissue donation is defined as the act of giving life to others after death by donating his/ her organs to the needy suffering from end stage organ failure.

Body donation is defined as the act of giving one's body after death for medical research & education. Those donated cadavers remain a principal teaching tool for anatomists & medical educators teaching gross anatomy.

### **22. Can a dead body be left for medical education or research after the organs have been retrieved for donation?**

No, bodies are not accepted for teaching purposes if organs have been donated or if there has been a post – mortem examination. However, if only the corneas are to be donated, a body can be left for research.

### **23. How can I help in increasing organ donation?**

You can help by:

- i.) Becoming a donor, & talking to your family about your decision of saving lives of others.
- ii.) Promoting donation by motivating people at work place, in your community, at your place of worship, & in your civic organizations.

## **II. Organs & Tissues Transplant**

### **1. What is Transplantation?**

Transplantation is the act of surgical removal of an organ from one person & placing it into another person. Transplantation is needed when the recipient's organ has failed or has been damaged due to illness or injury.

### **2. What are the end stage diseases that can be cured by transplantation?**

Here are some end stage diseases which can be cured by the transplantation:

<b>Name of the Disease</b>	<b>Organs/ Tissue required for its Treatment</b>
Heart Failure	Heart
Terminal Lung Illnesses	Lung
Kidney Failure	Kidney
Liver Failure	Liver
Diabetes	Pancreas
Corneal Blindness	Eye
Heart Valvular Disease	Heart Valve
Severe Burns	Skin

### **3. Who will tell me about the Transplant process?**

Transplant Coordinator & Treating Registered Medical Practitioner will explain you about the process of Transplant.

### **4. Who is transplant coordinator?**

Transplant Coordinator means a person appointed by the hospital for coordinating all matters relating to removal or transplantation of Human Organs or Tissues or both & for assisting the authority for removal of human organs.

Though their work is more related to deceased organ donation, they are responsible for living organ donation also. The current Transplantation of Human Organ Act (THOA) envisages that every hospital doing transplant activity, whether retrieval or organ transplantation must have a transplant coordinator in the hospital before the centre is registered for transplantation under the act. Transplant coordinator is a pivot of the organ donation & transplantation.

### **5. What is the role of a transplant coordinator in Organ & Tissue Transplant?**

The transplant coordinator has to counsel the grieved family, make them comfortable & approach the subject of eye donation and later on solid organ donation.

If the family gives consent for organ retrieval, then the coordinator has to inform the Nodal Officer & coordinate with the ICU staff to maintain the patient on ventilator & organize organ retrieval. The coordinator has to ensure that all paperwork is correctly done & that the family receives the body as soon as possible.

## **6. Is there any insurance cover for organ transplant costs?**

Till few years back, transplant cost both for donor as well as recipient was not covered by most of the insurance companies. Now a days, many insurance companies are covering cost related to transplant. It will be better to be sure when you are going for insurance.

## **7. Is there any age limit to be registered for transplant?**

Yes, patient should be fit for transplant & age is one of the criteria for assessing fitness of patient for transplant.

## **8. What is waiting list for Organ Transplant?**

A list of people waiting for receiving an organ.

## **9. How does someone get on the waiting list?**

The patient can register for inclusion in the waiting list through a registered transplant hospital. The treating physician of the hospital shall make an evaluation (based on medical history, current condition of health, & other factors) & decide if the patient needs a transplant & meets the criteria to be listed. Like for kidney transplant, other than blood group, main criteria is time, since patient is on regular dialysis. Similarly, for other organs, criteria are different based on medical history, current condition of health, and other factors.

## **10. How can I know that I am fit to be listed for organ transplant?**

Every patient who has developed end stage organ failure may not be fit for organ transplant. Basic principle is that patient must be screened on medical grounds (based on medical history, current condition of health, and other factors) for the development of end stage organ failure. Your treating doctor will decide whether you are medically fit for transplant and other issues before listing in the wait list.

## **11. How long will I have to wait?**

Once you are added to the national organ transplant waiting list, you may receive an organ on the same day, or you may have to wait for many years. Factors affecting are: how well you match with the donor, how sick you are, & how many donors are available in your local area compared to the number of patients waiting.

## **12. Why waiting list is so long?**

There is a huge disparity between demand & supply for transplant. There are more numbers of patients requiring different organs as compared to number of organs available for transplantation. That is why there is urgent need to create awareness about organ donation. As more persons decide to take the pledge & donate organs, the waiting list will go down.

## **13. What is the process to find a right donor?**

When a transplant hospital adds an individual (patient) to the waiting list, it is placed in a pool of names. When any deceased organ donor becomes available, all the patients in the pool are compared to that donor. Factors such as medical urgency, time spent on the waiting list, organ size, blood type & genetic makeup are considered.

#### **14. How long will it take to get a cadaver's organ?**

There is no time line on how long one will have to wait for an organ that the individual requires. This depends on his/ her medical situation & how frequently organs are becoming available in a city or state.

#### **15. Do I have option other than organ transplant?**

This query can only be answered by the treating doctor depending upon medical condition & stage of damage of the organ. For example, in a case of kidney failure, dialysis is an alternative treatment & for kidney failure patient, transplant is usually not an emergency. Also, for a heart failure patient, some patients can be maintained on artificial cardiac assistive devices. Similarly for other organs, the criteria are different, that can be maintained on medical therapies for the time being.

#### **16. Is it possible to know my status in the waiting list?**

Yes, you may know your status in the waiting list as this is a quite transparent system. But this will not help you significantly as getting an organ depends on many other factors other than just waiting list number.

#### **17. Do I need to be always prepared to receive call for transplant?**

Yes, it may be better to be mentally prepared & have some funds for an urgent organ transplant. Cadaver transplant is mostly on urgent basis. That is why it is better that your investigations for cadaver transplant are updated all the time so that whenever you receive a call, you can get the organ. Getting a cadaver organ is a gift & one should not miss it.

#### **18. If I get a call for transplant, will I definitely get the organ?**

No, getting a call for transplant does not mean that you will definitely receive an organ. The transplant team will examine your immediate fitness for transplant. There is a possibility that the tests done just before possible transplant may not be normal to make you fit for transplant. Further, more than one patient is called for possible transplant & there may be a chance that someone else will be more fit than you for that particular organ transplant.

#### **19. Would a donor's or recipient's family ever know each other?**

No, in Cadaver Organ Donation Programme confidentiality is always maintained, unlike in the case of living donors who usually already know each other.

If the family wishes, they will be given some brief details such as the age & sex of the person or persons who have benefited from the donation. Patients who receive organs can obtain similar details about their donors. It is not always possible to provide recipient information to donor families for some types of tissue transplant.

Those who wish to exchange anonymous letters of thanks or good wishes can do it through the transplant coordinator. In some instances, donor families & recipients could be arranged to meet.

#### **20. What is the protocol to maintain waiting list?**

As per protocol, patients who require cadaver organs are put in the waiting list. But in India, number of patients requiring organs are more as compared to number of organs available.

There are two types of waiting list: one is urgent waiting list & another one is regular waiting list. Urgent listing of patients for cadaver organ transplant is primarily based on medical criteria, i.e. patient needs organ on urgent basis otherwise he/ she may not survive.

Regular waiting list is also based on medical criteria & these criteria are different for different organs. Like for kidney transplant, main criteria is time spent on regular dialysis. Similarly, for other organs, criteria are different.

### **21. What is the protocol for organ distribution?**

The organ(s) would be distributed locally within the State first, & if no match is found, the organ(s) are then offered regionally, & then nationally, until a recipient is found. Every attempt would be made to utilize the donor organ(s).

### **22. How are donated organs matched with patients?**

Many medical factors need to match to ensure a successful organ transplant. Blood group is one of the major factors taken into account. Organ size of the donor & recipient is also considered. For kidneys, another important factor is tissue matching which is more complex than blood grouping matching & also takes more time. The best results can be achieved if there is a perfect kidney match.

There is a local, regional & national computerized list of patients waiting for an organ transplant. Most of the time, computer will identify the best matched patient for a particular organ & organ is offered to the transplant unit who is treating that patient. Also, priority is given to patients who most urgently need a transplant. NOTTO operates the waiting list & organ allocation system. It works round the clock, every day of the year. In case of tissues, matching is usually not required.

### **23. Can my organs be given to a foreigner also?**

As per the Transplantation of Human Organ Act 1994 & subsequent amendments, sequence of allocation of organs shall be in the following order: State List → Regional list → National List → Person of Indian Origin (PIO) → Foreigner.



### **III. Living Donor Related Transplant**

#### **1. What is living donor organ donation?**

Means a person during his life can donate one kidney (one kidney is capable for maintaining the body functions), a portion of pancreas (half of the pancreas is adequate for sustaining pancreatic functions) & a part of the liver (the segments of liver will regenerate after a period of time).

#### **2. Can I donate organ while I am still alive?**

Yes, but not all organs & tissues can be donated. Only few organs can be donated during life. The most common organ donated by a living person is a kidney, as a healthy person can lead a completely normal life with only one functional kidney. Kidneys transplanted from living donors have a better chance of long – term survival than those transplanted from deceased donor. Nearly 90% of all kidney transplants currently in India are from living donor. In addition to kidney, part of a liver can be transplanted & it may also be possible to donate a segment of a lung and, in a very small number of cases, part of the small bowel. For all forms of living donor transplants the risk to the donor must be considered very carefully. Before a living donor transplant can go ahead there are strict regulations to meet and a thorough process of assessment and discussion.

#### **3. What are the different types of living organ donation?**

Living Near Related Donors: Only immediate blood relations are accepted usually as donors viz., parents, siblings, children, grandparents & grandchildren (as per THOTA Rules, 2014). Spouse is also accepted as a living donor in the category of near relative & is permitted to be a donor.

Living Non – near Relative Donors: These are other than near relative(s) of recipient or patient. They can donate only for the reason of affection & attachment towards the recipient or for any other special reason.

SWAP Donors: In those cases where the living near-relative donor is incompatible with the recipient, provision for swapping of donors between two such pairs exists, when donor of first pair matches with the second recipient & donor of second pair matches with the first recipient. This is permissible only for near relatives as donors.

#### **4. Is there age limit for living donor?**

Yes, there is some age – limit for living organ donation. Living donation should be done after 18 years of age.

#### **5. What is Swap donation?**

Sometimes in the family, there is a potential related donor who is otherwise willing but due to blood group mis – matching criteria or due to some other medical reasons, is not fit to donate organ to that particular recipient in family. Further, in another family similar situation exists. However, in these two families, donor of one family may become medically fit for recipient of other family & vice versa. These two families then make a pair & make organ transplant possible for these two recipients of different families. This is called swap donation transplantation. Swap transplant is legally permitted in THOA (Amended) Act 2012.

## **6. Will I become medically unfit for organ donation?**

No, it is basic principle of living donation program that person remains absolutely healthy for the rest of his/ her life after donation. Thus, donor is not medically unfit for any purpose. However, in certain situation, living organ donor is treated differently. Like in the Armed Forces, an organ donor is not taken as normal & donor faces issues related to Promotion in job etc.

## **7. Is it possible to receive organs from a friend or other than near relative?**

As per Transplantation of Human Organ Act 1994 (& subsequent amendments), any living person other than near relative can also donate organ for the reason of affection & attachment towards recipient or for any other special reason. Such cases have to be approved by the Authorization Committee of the Hospital, where the transplant is going to take place. Approval of Authorization Committee is mandatory in all other than cases involving relatives.

If such Authorization Committee does not exist in the Hospital, then it can be approved by the respective District or State level Authorization Committee of the District (or State, if no Committee at District level), where the transplant hospital is located.

## **IV. Deceased Donor Related Transplant**

### **1. What is Cadaver/ Deceased?**

The Oxford Dictionary defines 'Cadaver' as 'a dead human body'. Medically, a 'Cadaver' is a corpse used for dissection & study. In the area of Organ Transplantation, 'cadaver' refers to a brain-dead body with a beating heart, on life support system.

### **2. What Organs & Tissues can a Deceased donor donate?**

If different organs and tissues are in medically fit conditions, following organs and tissues can be donated:

<b>Organs</b>	<b>Tissues</b>
Two Kidneys	Two corneas
Liver	Skin
Heart	Heart Valves
Two Lungs	Cartilage/ Ligaments
Intestine	Bones/ Tendons
Pancreas	Vessels

### **3. What is Brainstem Death?**

Brainstem death is cessation of function of the brainstem due to an(y) irreversible damage. It is an irreversible condition & the person has died. It is also called "Brain Death" in India.

A brainstem dead person cannot breathe on his/ her own; however, the heart has an inbuilt mechanism for pumping as long as it has a supply of oxygen & blood. A ventilator continues to blow air into lungs of brainstem dead persons, & their heart continues to receive oxygenated blood & medication(s) may be given to maintain their blood pressure. The heart will continue to beat for a period of time after brainstem death – this does not mean that the person is alive, or that there is any chance of recovery.

The declaration of brainstem death is made with accepted medical standards. The parameters emphasize the 3 clinical findings necessary to confirm irreversible cessation of all functions of the entire brain, including the brainstem: (1) Coma (loss of consciousness) with a known cause, (2) Absence of Brainstem Reflexes, & (3) Apnoea (absence of spontaneous breathing). These tests are carried out twice at the interval of at least 6 – 12 hours by the team of Medical Experts. Brainstem Death is accepted under the Transplant Human Organ Act since 1994.

### **4. Is Brainstem Death legally accepted as death?**

Yes, as per the Transplantation of Human Organs Act 1994, Brainstem Death is legally accepted as death.

### **5. Who will certify the Brainstem Death?**

As per THOA 1994, Board of Medical Experts consisting of the following will certify Brainstem Death:

- 1.) Doctor in charge of the hospital (Medical Superintendent)
- 2.) Doctor nominated from a panel of doctors appointed by the Appropriate Authority
- 3.) Neurologist/ Neurosurgeon/ Intensivist nominated from a panel appointed by the Appropriate Authority.
- 4.) Doctor treating the patient.

The panel of four doctors carries out the tests together to certify brain death.

### **6. Who explains to the family about the brainstem death?**

The doctor (Intensivist/ Neurologist/ Neurosurgeon) who is treating the patient will explain to the family about brainstem death.

### **7. If the family is willing to donate organs of the potential donor, how can they proceed for more information in terms of brainstem dead?**

The family can approach the counsellor of the hospital, the transplant coordinator or the doctors & nursing staff of the ICU.

### **8. What are reasons for time delays in deceased organ donation?**

Confirmatory tests for brain death have to be done twice within an interval of six hours between the tests. Once consent for organ donation has been obtained, coordinating the process of organ retrieval takes time.

Organ retrieval from deceased donors involves many hospitals, & transplant teams should ensure that the donated organs match as perfectly as possible with the recipient. If it is a medico legal case, a post – mortem has to be performed & this involves both the police as well as the Forensic Medicine department.

### **9. How quickly should the donated Organs by a deceased donor, be transplanted?**

Healthy organs should be transplanted as soon as possible. Different organs can be transplanted within different time frame as mentioned below:

<b>Organs</b>	<b>Time Frame of Transplantation (in hours)</b>
Heart	4 – 6
Lung	4 – 8
Intestine	6 – 10
Liver	12 – 15
Pancreas	12 – 24
Kidney	24 – 48

### **10. Who will receive my organs?**

Your vital organs will be transplanted into those individuals who need them most urgently. Gifts of life (Organs) are matched to recipients on the basis of medical suitability, urgency of transplant, duration on the waiting list & geographical location. NOTTO & its state units (ROTTO & SOTTO – U. P.) will work round the clock, every day of the year & cover the whole of the country. Tissue is very occasionally matched, e.g. for size & tissue type, but otherwise is freely available to any patient in need of a transplant.

**11. Who can give consent for organ donation after brainstem death?**

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.

**12. If my family refused cadaver organ donation, will my treatment be affected?**

No. Even though your family refuses for organ donation, the treatment will be carried out as per the clinical condition. Organ donation process is never linked with your appropriate treatment.

These two are separate entities. A completely different team works for organ donation. Also, doctors involved in transplant operation are never involved in the donation process with the family of potential donor.

**13. Can I be sure that Doctors will try to save me if I am registered as a potential organ donor?**

Yes, it is Healthcare professional's duty to save life of the patient first. Despite of all efforts, if the patient dies, organ & tissue donation can then be considered & a completely different team of retrieval & transplant specialists would be called in.

**14. If I carry a donor card, will my organ be taken out without my family being asked?**

No. Even though if you carry a donor card, your immediate family members & close relatives will be asked for donation of organs & tissues. The consent is mandatory from the person lawfully in possession of the dead body, before donation can be carried out. If they refuse, then organ donation will not take place.

**15. Is it possible that I can express my wish to donate organs to some people & not to others?**

No. Organs & tissue cannot be accepted unless they are freely donated. There is no such condition that can be accepted in terms of potential recipients. You can express your wish to donate specifically which Organ &/or Tissue, you want to donate.

**16. Is there any charge(s) applicable to my family for organ/ tissue donation?**

No. There is no additional charge to family of potential organ donor. Potential donor needs to be medically maintained in ICU till the time of donation. From the time family agrees to donate organs & tissue, all charges are borne by the treating hospital & donor family is not charged any further.

**17. Does organ/ tissue removal affect cremation/ burial arrangements or disfigure the body?**

No. The removal of organs or tissues will not interfere with customary funeral or burial arrangements. The appearance of the body is not altered. A highly skilled surgical transplant team removes the organs & tissues which can be transplanted in other patients. Surgeons stitch the body carefully, hence no disfigurement occurs. The body can be viewed as in any case of death & funeral arrangements need not be delayed.

**18. Can organs be removed, after death, at home of the deceased?**

No. It can only be removed when a person is declared as brainstem dead in the hospital & is immediately put on a ventilator & other life support systems. After death at home, only eyes & some tissues can be removed.

**19. What, if I had pledged to donate Organs, but my family refuses?**

In most situations, families agree of donation if they knew that was their loved one's wish. If the family, or those closest to the person who has died, object to the donation when the person who has died had given their explicit permission, either by telling relatives, close friends or clinical staff, or by carrying a donor card or registering their wishes on the SOTTO – U. P./NOTTO website, healthcare professionals will discuss the matter sensitively with them. They will be encouraged to accept the dead person's wishes. However, if families still object, then donation process will not go further & donation will not materialize.

**20. Is there difference in organs between heart beating donor or donor after cardiac death?**

Yes. Heart beating donor means the patient has been declared as Brainstem Dead, & his/ her organs can be retrieved while their heart is still beating with the assistive devices. Beating heart keeps the blood supply intact to organs & there is no damaging effect of low blood supply to organs.

In case of donation after cardiac death, heart stops beating & there is no blood supply to the organs. Because of that, donation after cardiac death has to be done immediately, as without blood supply, the organs will not be viable for use after a certain period of time.

**21. Why can organs of a brain dead patient be used for transplantation & not those of a patient who has died of a cardiac arrest?**

Solid organ donation (heart, lungs, liver, pancreas, kidneys) requires blood circulation to be maintained in these organs until retrieval. This is possible in brainstem death, where the functioning of these organs can be supported for some time.

However, organs after cardiac death can also be harvested, provided the time gap is minimal.

## **V. Legal & Ethical Issues**

**1. What is National Human Organs & Tissues Removal & Storage Network?**

The Central Government has established a National Human Organs & Tissues Removal & Storage Network named NOTTO, which stands for National Organ & Tissue Transplant

Organisation. NOTTO has five Regional Networks known as ROTTO (Regional Organ & Tissue Transplant Organization) & each Region of the country will develop their SOTTO (State Organ & Tissue Transplant Organisation) in every State/ UT.

SOTTO – U. P. is the SOTTO for the state of Uttar Pradesh, & it was established in October, 2019 in the Department of Hospital Administration, Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow, U. P.

Each hospital of the country related to transplant activity, whether as retrieval or transplant, has to link with NOTTO, through ROTTO/ SOTTO as a part of National Networking.

## **2. What is National Registry?**

The national registry for organ donation & transplant is as follows:

### **A. Organ Transplant Registry**

The Organ Transplant Registry shall include demographic data about the patient waiting for transplant (Organ/ hospital wise waiting list), donor (Living Donor including Related Donor, Other than Near Related Donor, Swap Donors & Deceased Donor), hospitals, follow up details of recipient & donor etc., & the data shall be collected from all retrieval & transplant centres.

Data collection may preferably be through a web-based interface or paper submission & the information shall be maintained both specific organ wise & also in a consolidated format.

The hospital or Institution shall update its website regularly in respect of the total number of the transplantations done in that hospital or institution, along with reasonable detail of each transplant & the same data should be accessible for compilation, analysis & further use by authorised persons of respective State Governments & Central Government.

### **B. Organ Donation Registry**

The Organ Donation Registry shall include demographic information of donor (both living & deceased), hospital, height & weight, occupation, primary cause of death in case of deceased donor, associated medical illnesses, relevant laboratory tests, donor maintenance details, driving license or any other document of pledging donation, donation requested by whom, transplant coordinator, organs or tissue retrieved, outcome of donated organ or tissue, details of recipient, etc.

### **C. Tissue Registry**

The Tissue Registry shall include demographic information on the tissue donor, site of tissue retrieval or donation, primary cause of death in case of deceased donor, donor maintenance details in case of brainstem dead donor, associated medical illnesses, relevant laboratory tests, driving license or any other document pledging donation, donation requested by whom, identity of counsellors, tissue(s) or organ(s) retrieved, demographic data about the tissue recipient, hospital conducting transplantation, transplant waiting list & priority list for critical patients, if these exist, indication(s) for transplant, outcome of transplanted tissue, etc.

### **D. Organ Donor Pledge Registry**

The National Organ Donor Register is a computerized database which records the wishes of people who have pledged for organ & tissue donation. Person during their life can pledge to donate their organ(s) or tissue(s) after their death through **Form 7** and submit it in paper or online to the respective networking organization (SOTTO – U. P./ ROTTO/ NOTTO) & pledger has the option to withdraw the pledge through intimation.

There are many hospitals & organizations those are also maintaining the list of persons who have pledged organ donation with them, which will be passed to SOTTO – U. P./ ROTTO/ NOTTO for National Register.

### 3. What is legal position on Organ Donation?

Organ Transplantation & Donation is permitted by law, & covered under the “Transplantation of Human Organs Act 1994” (& subsequent amendments), which has allowed Organ Donation by live & Brainstem dead donors.

In 2011, amendment of the Act also brought in donation of human tissues, thereby calling the amended Act “Transplantation of Human Organs & Tissues Act 2011” (THOTA 2011).

The Rules for the THOTA 2011 were published in 2014, & are known as “THOTA Rules 2014”.

### 4. Can people buy/ sell organs?

No. As per Transplant of Human Organ Act (THOA 1994 & subsequent amendments), buying/ selling of organ in any way is punishable & has a significant financial as well as judicial punishment. Not only in India, but in any part of world, selling of an organ is not permissible.

### 5. Whom do I report, in case, I find that there is a sale or organs?

In case, anybody submitting false records or any other delinquency, it should be reported to the Appropriate Authority of the State Government, Department of Health & Family Welfare. Any hospital, Authorization Committee, or a person can approach the State Appropriate Authority. The Appropriate Authority can file a case against the party.

As per the Amended THOTA 2011, the offenses & their punishments are as follows:

<b>Offence (as per amended THOTA 2011)</b>	<b>Imprisonment</b>	<b>Fine (in ₹)</b>
Removal of organs without authority	10 years	₹ 20 Lakh
Removal of organs without authority – Penalty for Registered Medical Practitioner (RMP)	1 <sup>st</sup> Offence: De – Registration for 03 years	2 <sup>nd</sup> Offence: Permanent De – Registration
Commercial dealing in organs, falsification of documents	05 to 10 years	₹ 20 Lakh to ₹ 1 Crore
Any violation of amended THOTA 2011	05 years	₹ 20 Lakh

### 6. What are the ethical concerns with living unrelated donations?



Doctors are concerned with the possible emotional/ financial exploitation of donors, by the recipient's families, & from transplant hospitals. They are worried that, with the increasing demand of organs, the rights of the poor donor to live with dignity may be abused.

Transplant hospitals have become more careful with a good system of screening in place, & an Authorization Committee of Hospital/ District/ State scrutinizes all the applications. Today, Living Unrelated donations have become more transparent & streamlined.

### **7. What is "Required Request"?**

Required request is a way of getting consent of the person for the cadaver donor transplantation. Any person, who wishes to donate his/ her organ & tissues after his/ her death, has to affirmatively make a pledge that his/ her organs after death can be used for transplantation & saving life of other person.

At the time of death, Hospital staff approaches the family of the deceased person for donating their loved ones organs & tissues to save life of others. This approach is also called as "opting – in" approach.

### **8. What is "Presumed Consent"?**

In the presumed consent approach, every person is supposed to be agreeing for organ donation at the time of death, unless the person has decided during his/ her life time that he/ she is not willing for organ & tissue donation after death. This system is also called "opting – out" system.

There are countries in the world who have presumed consent approach for organ donation & they believe that presumed consent approach usually increases organ donation rate. However, all do not agree for the same. India does not follow this approach.

### **9. What is "Informed Consent"?**

Informed consent is a process, which is not specific to organ & tissue donation. This is a process of reaching an agreement based on a full understanding of what will take place, in the form of medical treatment. Informed consent involves information sharing as well as the ability to understand & freely make a choice in relation to medical treatment.

### **10. What is National/ NOTTO Organ Donor Register?**

The National/ NOTTO Organ Donor Register is a computerized database which records the wishes of people who have pledged for organ & tissue donation & decided that, after their death, they want to leave a legacy of life for others. There are many hospitals & organizations that are also maintaining the list of persons who have pledged organ donation with them, which will be passed to SOTTO/ ROTTO & (then onto) NOTTO website for National Register.

### **11. Who can join the National/ NOTTO Organ Donor Register?**

Everyone, irrespective of age or health, can join the National/ NOTTO Organ Donor Register. Joining the Register expresses a wish to help others by donating organs or tissues after death but importantly, joining the Register also is a way to give legal consent or authorization for donation to take place.

## **12. What is the importance of a donor registry?**

A registry is an essential part of understanding who & where potential donors are. A registry gives a planner enough information to devise strategies to get more public cooperation & commitment towards organ donation. Having a registry in place allows doctors & transplant coordinators to check if a brain dead person wished to donate & then approaching the family for consent becomes easier. It helps in saving crucial time in the process of organ donation.

## **13. What are medico legal cases?**

When an accident victim is brought to a hospital for emergency treatment, a First Information Report (FIR) has to be filed by the family in the nearest Police Station. Such cases are usually called medico legal cases. Also, any medical treatment (for suicide, assault, poisoning or fall) which needs police to be notified becomes a medico legal case.

The police will conduct an inquest about the incident & take charge of the case. A forensic doctor will examine the patient & will allow or deny organ retrieval.

## **14. Is the police department involved in any way for the declaration of brainstem death?**

The police department has to be informed that a patient is brain dead if it is a medico legal case, but the declaration of brainstem death is only done by a panel of doctors.

## **15. Does Government of India financially support organ transplant?**

Yes. Government of India has started National Organ and Tissue Transplant Program (NOTP), under which patients "Below Poverty Line (BPL)" are supported for the cost of transplant as well as cost of immunosuppressant(s) after transplant, for the duration of one year. Other than this, renal transplant in all public hospitals is subsidized as per the Government of India policy.

## **16. Is it possible to jump the waiting list if someone is rich, well connected & influential?**

No. In India, the allocation of organs to recipients on the waiting list is based on predetermined criteria which include date of registration & medical criteria.

The wealth, race, or gender of a person on the waiting list has no effect on when & whether a person will receive a donated organ. The Transplantation of Human Organs Act of 1994 (& subsequent amendments) makes it illegal to buy or sell human organs in India.

## **17. If someone desperately needs an organ, is there any point in making a special appeal?**

A special appeal usually results in more people agreeing to become donors & can increase the number of organs pledged.

However, family appeals through the newspapers & television will not result in an organ immediately becoming available for the person on whose behalf the appeal was made. The

patient will still be on the waiting list, just like everyone else, & the rules that govern the matching & allocation of donor organs to recipients will still apply.

**18. Is it right to remove a healthy organ from a living person & give it to another?**

Organ transplantation is undertaken only as a lifesaving treatment. It is best for the transplant team to decide so as to whether to go ahead with a live organ donation, keeping in mind the two issues of doing no harm to the donor, and doing good for the recipient. Only the transplant team can decide whether the benefit to the patient is worth the risk faced by the donor. The transplant team takes into account the mortality & morbidity of the donor, though this cannot be accurately predicted.

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