

A dementia caregiver in India shares experiences and insights about life

FAQ on Organ/ Body/ Brain/ Eye Donation

This post provides basic information on organ/ body/ brain/ eye donation using an FAQ format, and includes links to sites with more information. It contains general information for the convenience of readers, and is NOT provided as expert/ authoritative advice, so please consult appropriate authorities as required. Decisions regarding donations are deeply personal, and this post does not attempt to advocate donations or enroll potential donors. I have no intention to persuade you about the merits or demerits of donation. **Also, this post is written for the Indian context.**

Why this page: According to the writer of this page, “After my mother died and I [donated her brain, eyes and body](#), many folks contacted me with queries that indicated conceptual confusions about types of donations and about the practical aspects of donating. I looked around for several months for a website I could refer them to, but most sites focused only on some types of donations or were geared towards enrollments, and did not discuss practical issues/ procedures applicable in India. So I decided to create this post.”

What is body donation?

Body donation is the donation of the whole body after death, for medical research and education. (See Wikipedia page: http://en.wikipedia.org/wiki/Body_donation)

Usually, this is done at a medical college (teaching hospital) and the body is used by medical students to study anatomy. It is also possible to donate a body/ some specific organs to specialized research institutes that may want to study a specific medical condition.

Body donation is different from organ donation.

What is organ donation (and/ or organ transplantation)?

Organ donation is donating an organ for use in **organ transplantation** (to replace a damaged/ diseased/ missing organ in a living person). The organ is removed from someone (live donor or deceased donor) and then transplanted in the recipient. The process involves complicated surgery and things like matching the donor and recipient, and medications to ensure the transplanted organ is not rejected. Read about organ transplant here: http://en.wikipedia.org/wiki/Organ_transplant

An organ can only be transplanted if it has not started decaying by the time it is transplanted.

Not all organs can be transplanted. Examples of currently feasible organ transplantations are: Kidneys, heart, pancreas, liver, lungs. Examples of organs not currently transplanted are: Brain (For updates and complete list, one possible source is the wikipedia page: http://en.wikipedia.org/wiki/Organ_transplant)

There are two categories of donors: **Live donors** and **deceased donors**.

“Live donors” are persons who donate (1) tissue that can be renewed by the donor’s body, and/ or (2) organs that the donor can live without because other organs in the donor’s body will take over the work of the removed organ. So since we have two kidneys, one kidney can be donated for transplant if the other kidney is considered good enough to take over the full workload. The live donor remains alive after the donation. Donations by live donors are feasible only for some types of organs. Countries have very strict laws on live organ donation to avoid organ trafficking. Examples of organ transplants possible from live donors are kidney and liver. Examples of organ transplants not done using live donors are heart and hand.

“Deceased donors” are persons who have been declared brain dead but are kept on life support till the organ(s) is removed. That is, the patients have been pronounced brain dead based on well-defined of neurologic criteria and are kept on life support so that their blood continues to circulate.

This prevents the organs from deteriorating. Once the required organs are removed for transplant, life support is ended.

Organ donation is not the same as “tissue donation.” (though many discussions on organ donation sites combine the two)

What is tissue donation (including eye donation)?

The term “tissue donation” refers to tissue that is removed from someone and placed in another person.

Examples of tissue that can be donated are: bones, skin, eyes, heart valves, tendons, cartilage.

Tissue can be used from a dead person for such tissue donation if it is removed within a short interval after death. See an explanation here: <http://www.nhsbt.nhs.uk/tissuedonation/about/>

Eye donation, the best known form of tissue donation, can be done by calling eye bank doctors at home (or at the hospital). After the removal, the eyelids are closed and the face looks placid—there is no disfiguration. The body can then be cremated/ buried etc., or used for body donation.

[Note that the removed tissue (including eye) may also be used for study/ research]

What is brain donation?

Brain donation is donating the brain of a dead person to the brain bank for the purpose of study/ research and involves removing the brain and preparing it in a way in which it can be studied. India has only one brain bank; it is called the Human Brain Tissue Repository and is at the Dept of Neuropathology, NIMHANS Bangalore.

The brain is removed from the donor after death, within a few hours (before the brain begins to deteriorate and becomes unsuitable for study). A pathologist makes an incision in the skull, removes the brain, and then stitches back the skin. Apparent disfigurement is minimal. The body is then returned to the family, who may take it for cremation/ burial etc., or donate the body for research.

The donated brain is used to educate people on the brain/ studied by researchers working on brain-related problems, for example ataxia, Parkinson, and dementias like Alzheimer’s.

The website of the department of neuropathology, NIMHANS is [here](#). For queries, you can contact Dr. Shankar (shankar@nimhans.kar.nic.in)/ Dr. Anita (amahadevan@nimhans.kar.nic.in), Human Brain Tissue Repository, Dept of Neuropathology, NIMHANS, Hosur Road, Bangalore, INDIA 560029, Phone: 91-80-26995130, 91-80-26563357

Some people say organ donation can be done after death, some people say it is after brain death. Is brain death the same as death?

Organ donation is possible after brain death, but **not possible** after the more typical type of death (which most of us call “death”).

Death, as most of us understand it, occurs when a person’s heart stops beating and no longer supplies blood to the entire body. While the terms employed by various agencies/ bodies may differ, simply put the person is dead enough for the attending physician to certify the death. Such death could occur at home or in a hospital, or in an accident/ homicide. Some people refer to this as “cardiac death”, but the terminology is not standard.

The key part of such “death”, when it comes to understanding donation, is that blood is no longer circulating in the body and so the organs start deteriorating and cannot be used for organ transplant. Tissue, on the other hand, can still be used after such death if removed within a few hours (so the eyes can be donated). And the body and its parts (like the brain) as such can be used for medical study and research.

Brain death is a medically defined condition where there is an irreversible end of all brain activity. It is a special situation where certain neurological criteria are used to determine whether the brain and spinal cord are damaged sufficiently to call the person dead. **In brain death, the person has no chance of recovering as the brain is irreversibly damaged and dead.** However, the blood is still circulating and so the organs do not start deteriorating and can be removed and transplanted.

India has legislation that defines the criteria for brain death, how it can be certified and by whom. It recognizes brain death as legal death. A brain-dead person’s organs can be removed for transplant if the next-of-kin gives consent. While the law in India accepts brain death as equal to death, family

members may have some difficulty accepting brain death as being the same as death because they may see the person's heart beating.

You can read India's Transplantation of Human Organs Act, 1994, here: <http://zcck.in/legal.html>. A general discussion on brain death is available here: http://en.wikipedia.org/wiki/Brain_Death

How can I donate my organs for transplantation?

Organ donation after death is only possible in case of a person being certified as brain dead. ***If you are declared brain dead, and, if your next-of-kin consents, then your organs (like liver, kidney, heart, pancreas, lung, etc.) will be evaluated for possible transplants.*** There is a strict procedure and legislation for declaring brain death and for deciding who shall receive the donated organs. Committees have been set up in states to handle enrolling persons who need transplants and to allocate organs available from brain-dead donors. Examples of zonal committees: Zonal Coordination Committee of Karnataka (see their Q&A at <http://zcck.in/faq.html> and <http://zcck.in/organ.html>) and Zonal Transplant Coordination Centre, Mumbai (<http://ztccmumbai.org/>).

In case you die in the more typical way, where your heart stops beating, your organs cannot be donated. However, your tissue can be donated (eyes, bones, skin, cartilage, heart valves, etc.) and used for another person. Also, your body and brain can be donated for study. ***These body/ tissue donations are possible only if done within the prescribed time frame, and if the next-of-kin gives consent.***

I've heard we can enrol for donation. I want to enroll so that I can be sure that my body is donated.

Enrollment is good because it expresses your intent to donate, and also gives you and your family an opportunity to learn more about the procedures that need to be followed after your death. Enrolling in schemes and also informing your relatives and others about this helps everyone know about your desire to donate (organs/ tissue/ body, whatever you want). It reinforces your commitment.

There are multiple places that have donor programs where you can enroll (more on this later).

However, please note that enrolling for donation does not ensure that donation will happen.

Also, donation can be done in most situations even without enrollment if the relatives are willing and sign the consent forms.

For donation to actually happen, the required donation steps have to be followed after your death.

Well, once I die, I obviously cannot donate my own body. What is the procedure others have to follow after my death to donate my body?

There are broadly two components:

1> Doctor certification of death

2> Consent for donation by the next-of-kin (involves signing required consent forms)

For typical death (where the blood circulation stops), donation can only take place after death is certified by a doctor. It needs to be a death from "natural causes" (see later question on natural causes and unnatural causes). As such death may happen at a variety of venues, persons who are keen on donating body/ brain/ tissue need to locate a suitable doctor and obtain the death certificate in a limited timeframe available so that the body remains usable for the donation and has not started decomposing.

For organ donation, donation is only possible if the criteria for judging and certifying brain death have been followed. Persons who are certified as brain dead are already in hospitals and under care, and so the doctors are already involved; they will guide the family/ relatives through the process. In fact, they are likely to request the family to consider organ donation and will do the required counseling.

What's this talk of natural and unnatural death? How does it affect body donation?

Body donation is only possible after a doctor certifies the cause of death, which means that the doctor knows enough about the situation of death, is satisfied that it occurred due to natural causes, and is willing to certify the cause of death. The disposal of the body is then the responsibility of the next-of-kin, who decide on how they wish to dispose the mortal remains—whether cremation, burial, or

donation. (In case the doctor doesn't know enough to be confident that the death is from natural causes, they will not issue any death certificate, and the body cannot be disposed off by the family).

Death may occur due to unnatural causes, or due to unknown causes which could include unnatural causes. For example, it may appear to be a case of poisoning. Or the person may die on the way to a hospital and be "dead on arrival"/ "brought dead" at the hospital. Or death may happen in an accident, or the person may be found dead under unknown conditions. In such cases, further investigation is required to ascertain the cause of death. The body may already be with the police in some cases. Or the doctors who examine the body (such as in a "brought dead" case at a hospital) will inform the police of the death (this is sometimes called raising a "death memo").

Once the police gets information about such a "unnatural" death, they have to ensure that investigation is done. This may involve an autopsy (or even multiple autopsies). They will also decide when and how the body is disposed; they may preserve the body or hand it back to the family.

When subjected to autopsy, the body is handled in ways that make it unsuitable for body donation. That is, once a body has been autopsied, the remains cannot be used for anatomical studies afterwards.

This procedural aspect gets confusing for families. For example, a person may die in sleep of apparently natural causes, but if no doctor is confident enough to provide a certificate stating the cause of death, an autopsy becomes inevitable. Even if the autopsy concludes that the death happened for natural causes, the body has now been subjected to an autopsy and has become unsuitable for body donation.

Frankly, I am very confused about death certificates and the procedures around them. Some people talk of the doctor issuing a death certificate, but doesn't the municipality issue it?

The term "death certificate" is commonly used for two different types of certificates, which leads to confusion. For the purpose of this section, we shall give them two different names, "*doctor's death certificate*" and "*municipal death certificate*". (This is not standard terminology, but I am using it here to make the discussion less confusing) Here's a rough understanding (please find out specific details as applicable to your state/ city):

When a person dies, a doctor has to check that the person is indeed dead and also be satisfied that the death happened from natural causes, and then certify the cause of death. In this certificate the doctor documents details such as the name and approximate age of the person, the address and other identity details, the date and time of death, and the likely cause (doctors are supposed to know the required format). The doctor signs this document and includes appropriate credentials, such as registration number with the medical council. *The doctor's certificate is a very important document and is necessary for all future actions related to the body's disposal, such as moving the body to a mortuary/ cremating/ burying/ donating the body.* (Please note that copies of the doctor's death certificate will be required at multiple places, so the original should be kept intact.)

The doctor's death certificate required for proceeding with donation is the same as the death certificate that is used for typical ways people dispose bodies, e.g., cremation, burial, etc.

Note that the death certificate given by the doctor immediately after death (which, in this section, we call the *doctor's death certificate*) is different from the "death certificate" required for processing inheritance (e.g., banks, property, insurance, etc.) (which, in this section, we call the *municipal death certificate*)

Every death has to be registered with the municipal authorities using their formal procedure. They issue a formal certificate (and "original" copies of it) after registering the death, and this formal death certificate (what we have called the *municipal death certificate*) is what is used for other processing. It is important to know that the documents required by the authorities for registering the death include documents issued/ signed by the doctor who gave the first death certificate. In case of body donation, these required documents include the body receipt certificate issued by the hospital; in case of cremation/ burial, the crematorium/ burial ground will provide the required documentation as suitable.

So both certificates are needed—the one from the doctor showing the cause of death, and the one from the municipal authorities showing the registration of death. What is the registration/ death certificate issue procedure that the municipal authorities use?

You will need to find out the applicable procedure from your local authority's office. Keep in mind that the death has to be registered within a certain number of days. The authorities will provide the prescribed formats that you will need to get filled and signed, and also list the required documents to be attached. For example, the doctor who checked for death and gave you the doctor's death certificate (see earlier question) may have to provide some information in the prescribed format to the authorities.

If the body has been donated, the hospital that accepts the body will have to provide a "body receipt" certificate. If you have donated eyes/ brain/ other tissue, but not the body—that is, you have used cremation/ burial/ other traditional methods for the body disposal, then the documents you use for the municipal death certificate are the typical set of documents.

There may also be other formalities. Procedures vary from place to place, and also keep changing. However, keep in mind that you may need more documents/ undertakings from the doctor who checked the death, and you will need a body receipt certificate or equivalent if you are donating the body.

You seem to pay a lot of attention to this doctor's certificate part. Can't we just get it from the hospital where the person was registered as a body donor?

The reason prospective donors and their families need to understand this aspect is because any delay in getting a doctor's death certificate could mean that the body/ tissue cannot be donated (decomposition may set in). Some amount of planning may make this part smoother.

For example, if someone dies suddenly at home, and if the person was not under a doctor's care, the family may not have a doctor to approach for the certificate. It is also possible that the attending physician is unwilling/ unable to come home for checking the person and issuing the certificate. Getting the certificate is even more difficult if the person dies at night because the family has to get the doctor to come home at the earliest and it is night.

Because the process of donation has to be started before decay sets in, the doctor's certificate must be obtained as early as possible. That means, the family must be in touch with a doctor who is willing to come home to confirm the death and issue the certificate. This becomes easier if the person is enrolled in a home nursing/ doctor-on-wheels type of service. If keen on donation, families should discuss the possible need for home visits in advance with the physician.

It is wrong to assume that the doctors/ hospital accepting the eye/ body donation will certify the death. Many families erroneously think that the eye bank doctors will come home and give the death certificate because they are doctors, and should be able to check for death. But the eye bank doctors will not give the death certificate. Often families use the physician who was attending the person before death, or some other doctor who knew the person who is dead, and is comfortable giving the certificate.

It is wrong to assume that if the dead person is taken to a hospital, the hospital will issue the doctor's death certificate. A person who is dead when brought to a hospital is declared "dead on arrival"/ "brought dead", and the hospital is obliged to notify the police, who will then initiate the autopsy and take over the body, as explained above. A body subjected to autopsy is handled in ways that make it unsuitable for body donation even if the police later on releases the body is back to the family.

We have a family doctor. Will he be able to help with the body donation process?

In some cases, maybe. Some doctors are informed and helpful.

Unfortunately though, many doctors are unfamiliar with tissue/ body donation procedures, or may even be misinformed about some things. Many, for example, don't know the criteria for eye

donations, and make assumptions about it. Many also don't know enough about the procedural details.

It is better to be familiar with all relevant procedures beforehand. You can contact the organizations that accept the donations, like eye banks, anatomy departments of medical teaching hospitals, forensic/ legal departments of hospitals, etc. You can consider enrolling in their donor programs if interested.

If the death takes place in a hospital, they'll handle all this donation business if we ask them, right?

Some hospitals are aware of and supportive of donations, but you cannot assume this will always be true. As donations are not common, the hospital staff may not know the procedure, or may see it as additional work. The amount of support you get will depend on the hospital and on the staff on duty. Please note that many hospitals may not have a system for donation, so they have to direct you to another hospital.

So if I want everything donated, in what order do I go about it?

In case of brain death, the organs and tissue will be donated first, and what remains can be used for body donation if suitable.

In typical death cases, the eyes/ brain are donated first, and the body can be then donated.

Every donation will require the doctor's death certificate and the consent form signed by the next-of-kin, and after every donation, the organization accepting the donation will issue a certificate about what was donated. For example, after the eyes are donated, the eye doctor who took the eye donation will give a certificate for this.

The final and most visible donation is when the whole body is donated. The family will no longer have the body with them after this. The receiving hospital/ college will provide a body receipt certificate which is the equivalent of a cremation/ burial certificate, and is needed for registering the death.

Note that families sometimes do the eye donation but don't donate the whole body. They then use traditional methods for disposing the body, like cremation/ burial. Donating the eye (and/ or brain) does not disfigure the body, which remains suitable for viewing and for the traditional cremation/ burial. This type of donation is often easier for families to accept as compared to doing a whole-body donation.

You mentioned that enrolment is not necessary for donation. Then what are the advantages of enrolling in donor programs?

By enrolling, you get access to information and resources, and have contact numbers to use when the donation has to be made. You can ask questions on procedures and eligibility.

Enrolling also means that you get a card you can carry with you or display to tell people what you want. It makes your intention quickly evident in case of accidents. It is also helpful in convincing relatives you are serious about donation.

Enrolling, however, does not mean that your next-of-kin is obliged to carry out your wishes and make the donation. Whether to donate or not is their prerogative. They may choose not to donate the tissue/ body, or the situation/ timing of the death may make donation infeasible.

So enrolling does not ensure that donation happens, but it increases the probability. The donation may even happen at another place; for example, if your intention to donate your eyes and body are well known to your family, and you die in another city, they can do the donation there through some other organization.

Do keep in mind that organizations that coordinate donations may close down or their phone numbers may change. It is better to opt for schemes/ organizations that are more reliable, and to periodically check that the organization still exists.

How do I enrol for donation/ get a donor card?

There are many types of body/ tissue/ organ donation types, and all enrollment schemes result in some type of donor card/ document being issued to the person who has enrolled.

Also, some organizations allow you to download and fill a donor card, which you can carry it with you. In this situation there is no enrollment, but the intention to be a donor is stated in the card present in your wallet, so it is visible in case there is an accident.

For body donation (anatomy study by medical students), contact medical teaching hospitals to ask if they accept body donations and if they have an enrolment scheme. Also, in addition to enrolling, find out the relevant procedures for actual donation. Some of them may even conduct regular lectures on donation, which you can attend along with family members.

Eye donation schemes can be checked out at any eye hospital, who should be able to guide you to various eye donation campaigns. Typically, eye donation doctors will come at home and remove the eyes if informed. Some major clubs like Rotary and Lions may also be handling eye donor programmers in at least some cities.

Brain donation is currently accepted at NIMHANS, Bangalore, and you can contact them to understand how to donate the brain, and also on whether and how this donation can be handled if the death happens in some other city.

Organ donation, possible only in case of brain death, is handled through zonal bodies. Information on enrolment schemes for your city will typically be available at any major hospital that does transplants; contact the liver diseases, kidney diseases, or heart diseases department, as they will be best informed about this.

There may be other ways to indicate your desire to donate organs, too, such as carrying a note on this in your wallet. Recently, a new scheme has been started in Karnataka to have a sticker on the driving license to indicate “organ donor.”

Do remember that phone numbers and addresses change, and that organizations that were earlier accepting donations may vanish, so check periodically whether the organization you enrolled with is still active.

Also, let your family have the enrolment details because in the event of your death, they are the ones who will have to do the donation.

I sometimes meet people who say they are donors. What does that mean?

People typically start calling themselves donors if they have expressed their intention to be donated after death and have enrolled in some scheme somewhere. They may also be carrying the donor card.

Keep in mind that these are all intentions. The person is expressing a desire about how his/ her body should be handled after brain death/ death. This intention will bear fruit only if the next-of-kin is able to act upon the intention and actually make the donation after the person dies.

However, becoming a “donor” is a good way to spread awareness and intention. It also encourages discussion and debate on the need for donation. If friends and relatives know of the intention, they will be more willing to ensure the donation actually happens.

What sort of situations could lead to a donation not happening though a person had enrolled?

We must remember that donation can only happen after death. At the actual time of death, many situations may happen that that result in no donation. For example:

- The family may simply forget that the person had wanted to donate. Death can be very overwhelming, and is often a time of emotional distress and confusion.
- Family members may not be able to locate the contact numbers, or they may not be confident of the donation procedure
- The next-of-kin may not give consent.
- Many close relatives may not want to go ahead with the donation, and may start objecting and putting pressure on the next-of-kin. It may seem simpler to just follow the traditional methods of cremation or burial.
- Death may not be detected for many hours (like death happening early in the night being noticed only in the morning) and so the body may have started decomposing and may not be suitable for some types of donation.

- There may be delay in getting a doctor's certificate, making donation infeasible as decomposition has set in.
- Death may take place in a different city where the family does not have the required contact numbers/ other information they need to proceed with the donation
- Death may be caused by accident/ other unnatural causes, leading to an autopsy, which means the body is unsuitable for donation

Within how much time after death must the donation be done?

Usually a few hours.

It is best to discuss this criterion at length with the organization(s) to whom you will be donating the tissue/ body. For example, they may suggest that you can place the body in a freezer in a mortuary if you cannot arrange for it to reach the destination immediately. Most hospitals have mortuaries with freezers, where people sometimes keep the bodies of their relatives while they are waiting for children to arrive from other cities/ countries for last rites. Please note that the mortuary will require a doctor's death certificate before accepting the body.

Also note that even if in doubt, you can contact the organizations after death, give them the time of death and ask if the donation will be accepted.

All this sounds very intimidating. Does anyone ever manage to donate?

Actually, the procedures are simple; the main problem is that not many people know them. In the rush after death, and in that emotional state, it is not possible to find out the details, because very few people have actual experience related to them.

If you have found out the procedures in advance, ensured that all relatives know the intention and are committed to donating, and also kept the contact numbers and procedures handy, there is a greater chance that the donation will occur.

Many persons donate the eyes/ brains/ body/ organs of their loved ones. This is usually easier if they are already conversant with what they will need to do (or have access to someone who knows) when the loved one dies, and when they are committed to taking the steps. Many families who are particular about donation plan for it and keep the required information handy. In some families, body donation is common enough to be like a tradition.

Some of the links below share experiences of persons who have successfully donated their loved ones.

I am keen to donate my body/ brain/ tissue/ organ but my family is not willing

Donation **cannot** happen if the next-of-kin is unwilling, as the **consent is essential**.

In case of your brain death, your family will have to consent to your organs being used for transplant. In case of the more typical form of death, your family will need to approach the receiving organization, inform them of the death, complete the formalities and hand over the body (or the eye/ brain).

If you are keen that your body be donated, you have to convince your family and get their commitment. **Howsoever keen you may be about donating, nothing will be donated unless your family follows the required steps after your death.** Please read this blog entry for a discussion on this topic. [The importance of preparing for body donation](#)

Some persons assume that enrolling in a donor program means the family is obliged to do the donation after their death. They think the family is legally obliged to fulfil this donation wish. This is not true. *There is no legal obligation on family members to respect any donation wish of the deceased.*

While no one can be sure of the time and manner of death, persons who want to donate their bodies can improve chances of donation if they:

- Ensure their intention is known to all family members and that the family members are comfortable with this, and willing to put in the extra effort required
- Make sure that all information related to the donation procedure is known to family members, and all relevant phone numbers are available
- Be regular about health check ups and have updated medical records so that there is no confusion on the state of health, and also that there are doctors involved in your health care

Your page only discusses eye, brain, body and organ donations. What about things like bone donation, etc.?

Many sorts of donation are possible. Unfortunately, most available information is around the above forms of donation (discussed on this page). However, some hospitals do handle other types of donation, and you can ask about them.

Donation of some body parts is also possible when you are alive, when some part is removed due to surgery, and this removed part may be of use to someone else. If you are having a surgery that involves removal of some part (such as in total knee replacement), check with the surgeon to find out about the potential of donation.