

Pledging to donate organs and tissues: are we missing a trick?

It is estimated that there are over 200,000 patients in our country who need kidney transplant, 100,000 need a liver, 50000 a heart, 20000 a lung. But have any of their own family members pledged to donate their organs?

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Mr Ghosh (name changed) walked into my fifth floor office at New Delhi. In his late sixties, rather shabby in a crumpled over-size kurta, worn out sandals and unshaven tired looking face, his lean frame seemed to wilt under the weight of a light cloth bag slung carelessly over the right shoulder. 'I have come all the way from Kolkata for your help' he said. Settling uncomfortably at the edge of a chair he went on to narrate how he was so lonely in this world. His wife died of cancer five years ago. Both children were abroad and rarely bothered to reach out to him. Life was meaningless. He leaned forward, placed a hand written note on my table and said 'This is my plea for donating my organs and eyes. Now that I have spoken to you and conveyed my wishes, I am going to jump out of the window. Please make sure that my organs and eyes are well utilized'. As I held his gaze I realized that he actually meant every word. Trying to maintain a semblance of normalcy, I offered him a glass of water. Rising from behind the desk, I pulled a chair and sat next to him, carefully planting myself between him and the window. 'Am afraid Mr Ghosh, I may not be able to help you. The law does not permit what you have planned', I said gently.

Most of us do not know how to pledge our organs and tissues for donation, or despite pledging, fail to understand the legal position and the process. Some countries like Spain and recently the United Kingdom, follow an opt-out system for deceased [organ donation](#). Every citizen is deemed to be an organ donor unless they have expressly specified not to do so during their lifetime. In India we have an opt-in system. In the unfortunate event of [brain death](#), the immediate family is presented with the opportunity to save several lives by consenting to donate organs and tissues of their loved one. The donor card for pledging our organs and tissues, made during our lifetime, has no legal standing. Making a pledge is not mandatory for donation but it does help the family in making a choice in difficult times. Therefore, it is of utmost importance that at the time of signing up for organ donation, one shares the decision with family members. The pledge to donate is not country, state or hospital specific. Following declaration of brain death by a team of four doctors, a team from the same hospital is mandated by law to approach the family and offer the choice of donating organs and tissues.

The process of pledging also needs to be simplified. Form 7 in Transplantation of [Human Organs and Tissues Rules 2014](#) requires signature of two witnesses, one of whom should be a near relative. Why have two witnesses if the donor card has no legal standing? During awareness drives on promotion of organ donation, the audience, despite their best intent, are unable to submit the signed pledge form on the spot for want of such witnesses. Even though most raise their hands in a group while promising to pledge, data suggests that only 10% manage to finally manage to send out completed forms. Online pledging is the way to go (www.notto.gov.in; www.fortishealthcare.com; www.mohanfoundation.org; www.organindia.org). The younger generation should be able to pledge on the move by using their smartphones. In case of online registration of pledge, the law requires that a hard copy signed by pledger and two witnesses be sent to the nodal networking organization. Why make the

process so difficult that an individual shies away from it? Paperless transactions need to be encouraged. Instead of signature of two witnesses, maybe we could ask the name the two persons in the family whom one plans to inform about the decision to pledge.

What must be done to make pledging more meaningful? There are several NGOs and hospitals that offer pledging facility in the country. But there is a problem. Every organization is issuing its own donor card without a Unique Identity (UID) number. There is a need to bring all such agencies under the umbrella of National/State Organ and Tissue Transplant Organization (NOTTO/SOTTO). The details of individuals who have pledged could be forwarded electronically to these authorities who could then issue the donor card with a UID number. At the same time NOTTO/SOTTO must ensure that the name of the NGO or hospital, that did all the hard work in promoting and facilitating the pledge, is mentioned on the pledging card. Why is there a need to go through the exercise of have a UID number? In the long term, we must link organ pledging to organ allocation. If two patients have the same medical need, priority should go to the patient who had signed an organ donor card or whose family members have donated an organ. Such a 'Don't give, don't get' policy, followed by Israel, is important to make people realize the importance of giving to others what they may want for themselves.

Few states have started including the facility of pledging at the time of issuing a driving license. The problem with that is that the individuals, in their eagerness to procure a license, would tick 'yes' to donation of organs and tissues without actually understanding what deceased organ donation is all about. A mandatory teaching e-module that incorporates the need for organ donation in the country, concept of brain death, difference between organ and tissue donation, the process of organ retrieval and transparency in allotment would be invaluable. A few questions related to the module could be incorporated into the test for driving license. The challenge of linking up the driving license number to the UID number allotted by SOTTO shall have to be worked out by each state.

The age at which pledging is allowed is also important. It has been reported that children as young as 11 years understand the concept of brain death. At the same time, there are concerns about anxiety in young minds while dealing with issues related to death. During an awareness event involving several schools, a little girl came up to me and said, 'Sir, the other school said each of us can save 8 lives after brain death, but should it not be nine? The liver can be split into two, isn't it! Add a heart, 2 lungs, 2 kidneys, pancreas, small intestine and that makes it nine.' I pulled out a chocolate from my pocket and handed it over with a smile. The legal age at which pledging is allowed in our country is 18. Often one sees a T-shirt or a placard that says 'I am an organ donor'. That can happen only if a [living donation](#) of a kidney or a part of the liver has been done. For deceased donation, one can only pledge to donate organs. One cannot be a deceased organ donor and live to talk about it! I 'support' organ donation makes much more sense.

Recently a family of 5 walked into my room looking very distraught. An elderly member pointed to the young lady in the group whose husband was dying of advance cirrhosis of liver. She pleaded that they required a 'liver donor at any cost.' I explained that living donation of a part of the liver was allowed only from a near relative between the age of 18 and 55 years. The option of joining the waitlist for deceased organ donation after brain death was explained. Reluctant to go for living donation, they wanted to know how much time it would take to get a liver. 'Deceased organ donation rate in India is one of the lowest in the world at less than one per million population and there will be several patients already listed for allotment of a liver' I explained. 'What do you mean' they shouted as one, 'we just allow him to die?' 'What kind of a country is this?' They all shook their head in utter disbelief. I went on to explain the hard work being put in by various agencies, the increasing awareness in the medical community and the public, the supportive legislation and how despite all limitations the nation still managed over 900 deceased donors in 2019. 'As all of you are so aware of the need for organ donation, am certain the five of you must have already pledged to donate your organs', I said. They looked at each other sheepishly. This is exactly where the problem lies. We only want for ourselves from the society but do not want to give back. It is estimated that there are over 200,000 patients in our country who need [kidney transplant](#), 100,000 need a liver, 50000 a heart, 20000 a lung. But have any of their own family members pledged to donate their organs?

I watched through the glass door of my consultation chamber as the family went up to the reception and picked up forms for pledging. The change was happening. Slowly, but it was definitely happening!