

Living Donor Advocacy

First Person: Why India Needs a Policy to Ensure that Organ Donors are Protected – and Respected



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Without donors, there is no transplant programme. We owe them more than gratitude. We owe them recognition and justice.

“You need to prepare for dialysis”

The words exploded in the room. The silence that followed was deafening – not the kind that soothes, but the kind that follows devastating news.

It was September 2009. I felt the ground collapse beneath me. Just months earlier, I had been diagnosed with end-stage kidney failure.

My daughter was just five. Would I be there for her birthdays? Her college years? Her future?

Then came a fragile thread of hope: a kidney transplant. Amidst my fear of dialysis, this felt like life itself. My family rallied. Without hesitation, my mother said, “Take mine.” Calm, unwavering, unconditional. But instead of relief, I was gripped with a different kind of fear. What if something happened to her? For months, I hesitated, torn between the will to survive and the guilt of causing her harm.

In 2010, after an agonising period of indecision, I underwent a successful transplant. As I emerged from anaesthesia, groggy and aching, my first words were, “How’s Mummy?” A nurse drew back the curtain in the recovery room. There she was – barely awake, turning her head towards me. Our eyes met in a moment of silent love, relief and overwhelming gratitude.

She had given me life – again.

Looking back, I now realise, we had never truly discussed what she might have to endure – the risks, the recovery and the emotional toll. We had no real way to assess the risk involved. We had moved forward blindly, placing our trust in the doctors.

That silence still echoes today through every living donor whose story remains untold.

Invisible presence

In 2016, I left my corporate career to work with MOHAN Foundation, a non-profit that promotes ethical organ donation. Since then, I’ve met dozens of living kidney and liver donors, many of them women. Their stories are powerful and yet often marked by emotional exhaustion, social pressure and loneliness.

One woman said, “I had no choice. If I’d refused, I would have been thrown out.” Another admitted, “The hospital is focussed only on the patient. I felt invisible – like just a means to an end.” A third confided, “My family was split – some insisted I donate because he is my husband, while others felt I shouldn’t feel pressured by duty or guilt.”

Too often, the donation is validated with a single thought: At least my loved one is doing well.

Gendered sacrifice

India’s transplant system relies heavily on living donors. In 2023, according to the National Organ and Tissue Transplant Organization (NOTTO), 84% of transplants in India were from living donors. Of these, 63% were women. Yet only 36% of recipients who received organs from living donors were female.

This is no coincidence. In patriarchal family structures, women are often expected to sacrifice quietly, unquestioningly, out of duty. The system not only accepts this – it relies on it. And yet, protections for these donors remain dangerously thin.

Illusion of consent

While living donors undergo medical clearance and sign consent forms, consent is often shaped by subtle and overt pressures – familial, financial and emotional.

Consent must be more than legal: it must be informed, voluntary, and free from coercion. This demands mandatory psychosocial evaluations and explicit screening for pressure, be it inheritance promises, emotional blackmail or family expectations. Donors should be empowered to withdraw at any stage – without fear, guilt or consequences.

And, we must reduce our dependence on living donors by promoting deceased organ donation. That is a more equitable and systemic solution.

Missing link

India urgently needs independent living donor advocates – trained professionals, separate from the transplant team, tasked solely with protecting the donor’s interests. These advocates should assess emotional and financial vulnerability, explain risks and rights, and uphold the donor’s autonomy. Such safeguards exist in many countries. In India, they are rare, misunderstood, or altogether absent.

After surgery, most donors are left to navigate recovery on their own. Long-term follow-up is patchy, and many drop out of the



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system altogether. Worse, they often bear out-of-pocket expenses; travel, accommodation, lost wages and complications.

India lacks a national donor support scheme. That must change. No one should face financial hardship for their altruism. Eliminating disincentives is key to protecting organ donation's voluntary nature.

India needs a National Donor Support Fund, under the NOTP, overseen by NOTTO, to provide financial protection for all donors regardless of income or hospital type. This fund should reimburse travel, lodging, and lost wages; provide free lifelong annual medical follow-up; offer government-backed health and life insurance; and support families of deceased donors.

International models offer guidance. The US Living Donor Protection Act ensures job and insurance safeguards. Israel provides tax breaks, paid leave, and lifelong healthcare. In India, the 42-day paid leave for central government employees who donate organs is a step forward – but it is far from enough.

Recently, NOTTO has signalled its intent to strengthen donor protections; but these efforts must go beyond symbolic gestures. We need a comprehensive, enforceable policy that treats donors with respect and give them the protection they deserve.

Policy action

Recent court rulings, particularly from Kerala, have affirmed donor's rights and dignity. These must now guide national policy. As transplant centres proliferate across India, donor safeguards must become mandatory.

Because without donors, there is no transplant programme. We owe them more than gratitude. We owe them protection, recognition and justice.

When I think back to that hospital curtain drawing open, to my mother's silent smile through pain, I know what it means to owe your life to someone else. But no one should have to sacrifice in silence.

Let us break that silence – for every donor who gave, and everyone who still might.

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