

Living Organ Donation by Persons with Certain Life-Limiting Illness

Summary and Goals

The purpose of this white paper is to provide an ethical analysis of living donation (kidney or liver segment) by persons living with life-limiting illness who want to be living organ donors. The paper concludes that living donation by clinically eligible individuals with life-limiting illnesses is, conceptually, an ethically sound practice, and that the determination of eligibility for living donation should be made by the individual's healthcare team.

Transplant hospitals may be reluctant to consider living donation by persons with certain life-limiting illnesses because:

- The individual may not meet standards currently required for living organ donation by transplant hospitals or regulatory guidelines because of a having a life-limiting illness.
- The individual may be at increased risk of complications or death after donation related to their life-limiting illness.
- Transplant hospitals must report living donor deaths to the OPTN or other regulatory authorities.

The goals of this white paper are to:

- Identify and address the ethical issues pertaining to living organ donation by persons with certain life-limiting illnesses.
- Identify the potential benefits and harms of living organ donation to persons with certain life-limiting illnesses.
- Provide an ethical analysis for the transplant community to consider if they decide to adapt, revise, or develop policies related to living organ donation to accommodate persons with certain life-limiting illnesses.

This white paper will address the scenario of an individual:

- Who wishes to be a living organ donor.
- Who has a progressive, incurable, chronic disease that is life-limiting (e.g., patients recently diagnosed with Amyotrophic Lateral Sclerosis (ALS) or Multiple Sclerosis (MS)). This white paper does not define or delineate the specific clinical criteria of life-limiting illnesses that would enable individuals with life-limiting illnesses to become living donors. Rather, the Ethics Committee recognizes that healthcare providers are in the optimal position to make the determination of whether an individual with life-limiting illnesses is clinically eligible for living donation on a case-by-case basis.
- Whose life-limiting illness (at the point of donation) would not put the individual at unreasonably high risk for an adverse outcome after donating, as determined by the individual's healthcare team at the transplant hospital.

- Whose risks of living donation, once the individual is deemed eligible for living donation by the transplant hospital, are evaluated mutually through a shared decision making process between the transplant team and the potential living organ donor.
- Whose life-limiting illness has not led to substantial reduction in the medical quality of the organ to be recovered and transplanted.

The OPTN/UNOS Ethics Committee (the Committee) reviewed and considered the limited published research and anecdotal reports on living organ donation by persons with certain life-limiting illness, and the reasons transplant hospitals may be reluctant to consider persons with such illnesses as living organ donors. Living donation by persons with certain life-limiting illnesses is not specifically prohibited under current OPTN Policy. The Committee considered the ethical principles guiding living donation, and concluded that persons with certain life-limiting illness should not be precluded from donation if those individuals can provide informed consent and meet current required informed consent and psychosocial and medical evaluation criteria required by the OPTN. The Committee understands that there may likely be a need for other OPTN Committees, in consultation with the transplant community, patients and their families, to propose and establish new and additional informed consent and psychosocial and medical evaluation criteria to adequately evaluate and protect potential living donors with certain life-limiting illnesses.

Based on this analysis, the OPTN could:

- Revise and expand criteria for living donation among those with life-limiting illnesses.
- Recognize the ethical justification of honoring the autonomy of persons with certain life-limiting illnesses as potential living organ donors.
- Support transplant hospitals and potential living donors by reducing disincentives and impediments to organ donation by persons with certain life-limiting illnesses.
- Make OPTN/UNOS regulatory oversight of transplant hospitals reasonable when individuals with life-limiting illnesses die from their underlying disease, and not from the living donation process itself.

OPTN Committees could establish explicit guidelines, propose new policy or amend existing policy to facilitate living organ donation by persons with certain life-limiting illnesses.

Background

Problem

As of March 2017, over 75,000 people were active on the organ transplant waitlist in the United States (U.S.).¹ The gap between those needing an organ transplant and organ availability continues to increase. Therefore, increasing the pool of organ donors, both deceased and living, is a critical public health need.

¹ UNOS. Transplant Trends. https://www.unos.org/data/transplant-trends/#transplants_by_donor_type

Since 2006, transplant hospitals have been required to report to the OPTN living donor deaths within two years of the donation date.

In 2013, the OPTN implemented new informed consent policies (*Policy 14.4. D: Living Donor Exclusion Criteria*) for living kidney donors. New informed consent policies for other types of living donors followed in 2014. These new policies included absolute contraindications (Living Donor Exclusion Criteria) to living donation (such as an active malignancy or diabetes) which may contribute to concern or reluctance to considering living donation by person with certain life-limiting illnesses.

Under current OPTN Policy, transplant hospitals may be reluctant to consider a potential donor with certain life-limiting illnesses even if they meet medical and psychosocial and informed consent criteria for living organ donation. Transplant hospitals could be concerned that under current OPTN *Policy 18.6 (Reporting of Living Donor Adverse Events)*, it would be required to report a living donor death and could face scrutiny even if the death was due to the life-limiting illness, and not the donor surgery. When a transplant hospital reports a living donor death, the hospital reporting the event would typically provide a narrative describing the circumstances of the death, and the death may not require further investigation. Because individuals with a life-limiting illness are expected to die from their disease, transplant hospitals recovering an organ from a living donor with certain life-limiting illness could have higher rates of living donor events that could result in unreasonable regulatory scrutiny for the transplant hospital by the OPTN, which may serve as a disincentive.

This Committee previously developed a white paper addressing the ethical considerations of imminent death donation (IDD). (See OPTN/UNOS White Paper entitled *Ethical Consideration of Imminent Death Donation*) IDD is a term that has been used for the recovery of a living donor organ immediately prior to an impending and planned withdrawal of ventilator support expected to result in the patient's death. IDD applies to at least two types of potential donors:

1. An individual with devastating neurologic injury that is considered irreversible and who is not brain dead. The individual would be unable to participate in medical decision-making; therefore, decisions about organ donation would be made by a surrogate or might be addressed by the potential donor's advanced directive.
2. An individual who has capacity for medical-decision making, is dependent on life support, has decided not to accept further life support and indicates the desire to donate organs prior to foregoing life support and death. In such cases, the potential donors can provide informed consent and consequently no surrogate decision making is needed. An example of this case might be an individual with high cervical spinal cord injury.²

In contrast, this white paper provides an analysis of potential living donors who:

- Have a life-limiting illness.

² UNOS Ethics Committee. Ethical Considerations of Imminent Death Donation. 2016.

- Meet the informed consent and psychosocial and medical evaluation policy requirements to be a living donor.
- Would donate and donation would be unlikely to dramatically alter their disease course.
- Would donate when it would not put the potential donor at unreasonably high risk, as determined by the transplant hospital, and decided upon mutually by the transplant team and the living organ donor.
- Have a life-limiting illness that has not led to a substantial reduction in the medical quality of the organ to be recovered and transplanted, as determined by the transplant hospital.

Definitions

The following definitions will apply for this white paper:

- **Life-limiting illness** is a term found in current palliative care and disability research literature and is used to describe a medical condition, disease or illness which is progressive and fatal and which cannot be reversed by treatment.

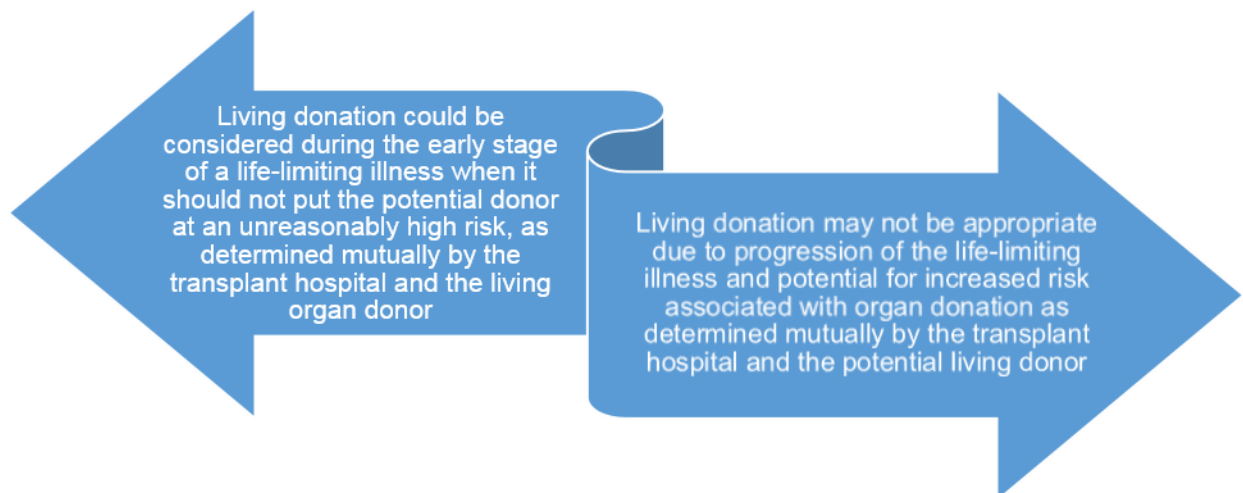


Figure 1 – Visual representation for when it may be appropriate for living organ donation by persons with life-limiting illness

- **Capacity** refers to the ability of an individual to comprehend relevant information, to understand the meaning and consequences of a decision, to determine if the decision is consistent with their values and preferences, and to effectively communicate their decision.³
- **Competency** is a specific legal term used to indicate that an individual understands an act. Competency is a prerequisite and the first element in the informed consent process.

³ Appelbaum & Grisso (1988). Assessing patients' capacity to consent to treatment. NEJM, 319: 1635-1638

- **Life Support** refers to a therapy or device designed to preserve life and includes, but is not limited to, supplemental oxygen or mechanical ventilation, intravenous fluid therapy, sugars and salts, drugs to improve circulation, antibiotics, transfusions, surgery, nutritional supplementation (e.g., parenteral nutrition or feeding via a feeding tube), dialysis, pacemaker, electrical defibrillation, heart or lung assistance devices, transplantation of organs, and sedation and temporary paralysis.

History of Living Organ Donation and Related Policies

Between 5,500 and 6,000 living solid organ donor transplants are performed each year.⁴ In September 2006, the OPTN Board approved a requirement for transplant hospitals to report to the OPTN all living donor deaths, and the failure of the live donors' native organ function, within 72 hours of transplant. The intent of the policy (*Reporting of Living Donor Adverse Events*) is to require timely reporting of deaths and serious events that affect the well-being of living donors. In 2013, the OPTN implemented new policy requirements for informed consent and for the psychosocial and medical evaluation of potential living donors.

Currently, transplant hospitals may face barriers to the evaluation and acceptance of living organ donors with certain life-limiting illnesses due to several important issues such as:

- The individual is not “healthy” in the sense that is usually required by the transplant hospital.
- The individual may be at increased risk of complications or death during or after surgery.
- Transplant hospitals must report living donor deaths to the OPTN, and are concerned that they could be scrutinized for reporting such events.

Empirical Evidence and Public Support

The Committee acknowledges that there is very limited available research on this issue.

A literature review yielded only one published study on outcomes of living donors who were “seriously ill”. The study, conducted in the Netherlands by Rakke and colleagues, included five kidney donors who were “seriously ill” (4.7% of all the living donors evaluated at this center).⁵ The “serious diseases” (comparable to what is referred to as “life-limiting disease” in the U.S.) of the living organ donors included Huntington’s disease (two living donors), stage III GOLD (Global Initiative for Chronic Obstructive Lung Disease) criteria for chronic obstructive pulmonary disease and severe emphysema, and grade II oligodendroglioma of right front lobe and multiple cerebral and caudal ependymomas (central nervous system tumors with extremely low capacity to metastasize from the central nervous system to the body).⁵ According to the authors, prior to donation, all five individuals were non-directed donors and were reported to be

⁴ United Network for Organ Sharing: Data. <https://www.unos.org/data/>

⁵Rakke YS, Zuidema WC, Hillhorts MT, Erdman RAM, Massey EK, Betjes MCH., Dor FJMF, Ijzermans JNM, Weimer W. Seriously ill patients as living unspecified kidney donors: Rational and Justification. *Transplantation*, 2015; 99(1):232-235.

psychologically healthy, had genuine motivations to donate, had adequate risk perceptions of the surgery, and their cognitive functioning was within the normal range.⁵ The motivations of the five seriously ill living donors are included in Table 1.

Table 1: Motivations to Donate (Rakke et al, 2015)

Living Donor	Reported Motivations
Donor 1	The reason for kidney donation was partly feelings of “uselessness” and “insecurity” about his own body. With the donation, he wanted to help a person in need of a kidney transplantation. Furthermore, donation was driven by his Christian beliefs.
Donor 2	She reported that her main reason to donate was her experience of not being able to help a loved one with a kidney disease who ultimately died because of the organ shortage. Furthermore, she was afraid that her organs would not be usable after her death and therefore wished to donate a kidney while still alive.
Donor 3	The reason for donation was based on his opinion that, at the moment, he was physically and mentally still healthy enough to donate a kidney. Moreover, he was aware of the fact that kidneys from living-donors function better than those from deceased donors. He reported: “By doing this I can give something back to society, just like my Mother would have done, because she was a really helpful person. I am sure she would have been proud of what I am going to do.”
Donor 4	His reason for donation was driven by the death of his cousin, who died from cystic fibrosis. He reported: “I know what it feels like to be critically ill and how much it would mean for one to recover. Now I’m seriously ill, but my kidneys are still suitable for transplantation purposes.”
Donor 5	The motivation to donate a kidney was the desire to help someone. Furthermore, her friend experienced kidney insufficiency for which she had received a kidney from an acquaintance.

The average length of stay in the hospital for the living donors was five days and the median follow up was 24.2 months. No surgical complications were reported.⁵ Normal serum creatinine and blood pressure were observed in all living donors after surgery.⁵ Pain and fatigue were reported by two living donors at three months post-surgical follow up. Neither of the two remaining donors showed a decrease in renal function at their last annual medical follow-up.⁵ During the post-donor nephrectomy follow-up period, three donors died from their disease: one donor died from ependymomas (2.4 years after donating), one donor died with physician assisted suicide (0.6 years after donating), and the third donor died with physician assisted suicide (4.9 years after donating).⁵ It should be noted that the sample size of this study was small (n=5), and that similar outcomes may not be replicated at other centers or with other individuals with serious or life-limiting illnesses. The OPTN does not have comparable outcomes data for non-seriously ill living donors in the Netherlands or seriously ill living donors in other countries including the U.S.

In the last decade, public interest in and awareness of individuals with life-limiting illnesses who desire to donate an organ has increased. Several news stories have been reported in the popular press in the last five years.^{6,7} The stories describe potential living donors with life-limiting illnesses (e.g., MS, Amyotrophic Lateral Sclerosis (ALS)) who were not approved

⁶<http://www.nydailynews.com/news/national/dying-michigan-woman-leave-donate-organs-article-1.1421125>

⁷ Mezrich J & Scalea. As they lay dying. The Atlantic. April 2015, Health.

⁸<http://www.theatlantic.com/magazine/archive/2015/04/as-they-lay-dying/386273/.1421125>

for organ donation by transplant hospitals. Motivations of these donors included a desire to save someone's life; the desire to donate one or more viable organs, which may ultimately not be possible as a deceased organ donor and could be more feasibly accomplished in a living organ donation setting; and a desire “to control her own destiny”. A recent survey of ALS neurologists across the U.S. indicates that one in four ALS patients may be interested in living donation. The survey found that a majority of these neurologists would support this opportunity for their patients, and that half of their patients had already inquired about such an opportunity.⁸

With any new transplant initiative, there is a potential to inadvertently affect public trust in unanticipated ways. The OPTN supports the importance of maintaining public trust and seeks to promote and preserve the integrity of the transplant system. The OPTN supports measures to uphold public trust which could include public education campaigns on the ethical and legal principles involved in living donation by persons with life-limiting illnesses. Additionally, if living donation by persons with life-limited illnesses is supported by the transplant community, the OPTN should investigate potential implications of this initiative on living donation rates, viability of transplantable organs, transplant centers, and effects, if any, on public trust.

Ethical Considerations of Living Donation by Persons with Certain Life-Limiting Illnesses

Living organ donation by persons with certain life-limiting illnesses is supported by the ethical principles of autonomy, beneficence, justice, and nonmaleficence. These principles designate what would make an action ethically sound insofar as the specified ethical principle is involved, and are usually considered to help determine what would be “right, other things being equal,” but may also be overridden by the weight of other ethical principles or virtues.

- **Respect for Autonomy** refers to the idea that actions are morally right insofar as they permit people to live according to their own life plans. It supports the idea of self-determination in that an individual’s functioning is independent or free from interference from others, and the individual can make decisions on their own behalf. Individuals who have life-limiting illness **and who are potentially eligible to be living donors**, but who are not permitted by the transplant community to be living organ donors, are denied their autonomy and meaningful choice. People with life-limiting illness are entitled to no less autonomy than those without life-limiting illness. As such, efforts should be made to allow interested persons the opportunity to donate if their health permits. Living organ donation may be perceived by individuals with certain life-limiting illnesses as a meaningful aspect of end-of-life decision-making. Respect for autonomy entails affirming the individual’s willingness to proceed with donation, and not that an individual’s decision to donate can overrule the transplant hospital’s determination of eligibility. Living donation by persons with certain life-limiting illness reflects the increased emphasis placed in the healthcare setting on patient-centered decision

⁸ Physician perceptions about living organ donation in patients with Amyotrophic Lateral Sclerosis” (Clin Neurol Neurosurg. 2017 Sep; 160: 125-129)

making and shared decision making approaches. These approaches entail a living donor's desire to provide greater input into treatment decision-making process with the healthcare team with regard to acceptable risks as well as determining whether the benefits of living donation outweigh the risks to themselves and the potential recipient.^{9,10}

- **Justice** is the principle that refers to the fair and equitable distribution of benefits and burdens. Allowing individuals with life-limiting illness to donate their organs permits the equitable distribution of the potential psychological benefits of donation as well as sharing the potential burden of donation.
- **Beneficence** is the principle that an action is right insofar as it produces benefit to the self or others. Living organ donation by persons with certain life-limiting illness potentially benefits the recipient by improving their length of life and quality of life. Accordingly, respecting the autonomy of persons with certain life-limiting illness who want to be living organ donors could save more lives through transplantation. A recipient's family members may also gain benefit especially if they have been involved in the transplant candidate's care or are affected by the transplant candidate's disease. Living donor organ transplantation may also benefit the living organ donor as it may accord with the living donor's sense of self-esteem and life meaning.¹¹
- **Nonmaleficence** refers to the principle of "do no harm" or doing the least harm possible. If the surgery does result in unacceptable harm, it violates the principle of nonmaleficence. However, as described below, at times, other principles may be considered that can justify taking actions that cause harm (such as the principle of double effect). In medicine, nonmaleficence may be better conceptualized as avoiding unreasonable risks rather than "do no harm" because medical treatments and surgery carry a potential for side effects and complications which may be harmful.

By taking these four principles into account, determining what is ethically sound medical practice requires trade-offs. Hence, nonmaleficence may be compromised in medicine to attempt to do good for the living donor organ recipient (beneficence) and to respect the living organ donor's wishes (autonomy). As with all cases of living donation, donors undergo medical risks, but the benefits of the donation may outweigh the risks to donors. Similarly, in the case of living organ donation by persons with certain life-limiting illness, although the act of surgery may bring harm, the potential benefits to the recipient and the living donor (beneficence), coupled with expressing respect for the donor's autonomy, may be more important considerations than the inherent medical risk to the living donor from organ donation.

⁹ Thiessen C, Gordon EJ, Reese PP, Kulkarni S. Development of a Donor-Centered Approach to Risk Assessment: Rebalancing Nonmaleficence and Autonomy. *Am J Transplant*. 2015 Sep;15(9):2314-23.

¹⁰ Gordon EJ, Butt Z, Jensen S, Lehr AL, Franklin JF, Sherman L, Becker Y, Chon J, Beauvais N, Hanneman J, McNatt G, Penrod D, Ison MG, Abecassis MM. Opportunities for Shared Decision Making in Kidney Transplantation. *American Journal of Transplantation* 2013;May;13(5):1149-58.

¹¹ Allen MB, Abt PL, & Reese PP. What are the harms of refusing to allow living kidney donation? An expanded view of the risks and benefits. *American Journal of Transplantation*, 2014; 14: 531-537.

Because this white paper aims to conceptually evaluate the ethical soundness of living donation by individuals with life-limiting illness, it is beyond the paper's scope to generate specific criteria or clinical practice standards to help establish equivalency between healthy and people with life-limiting illness in the context of living organ donor evaluation and selection. Living donation should only be considered if and when the individual would not be subject to unreasonably high risk as determined mutually by the transplant hospital and the living organ donor.

Yet, to respect the donor's autonomy, the most important consideration is that the transplant hospital properly disclose the magnitude of these risks to potential living donors so that potential living donors can evaluate these risks in light of their values and beliefs to make an informed decision. An individual with a life-limiting illness may plausibly have a higher (or lower) tolerance for the risk of donation-related complications compared to potential living donors in excellent health. Overall, the benefits to the transplant candidate and living donor frequently outweigh the risks.

Important Considerations for Living Donation by Persons with Certain Life-Limiting Illnesses

The following issues and scenarios may be considered in the context of living organ donation by persons with certain life-limiting illnesses.

Capacity and Informed Consent

In order to demonstrate an individual's capacity for informed consent, individuals with certain life-limiting illnesses must be able to engage in medical decision making, which entails comprehending the information, understanding the meaning and consequences of a decision, making an informed decision, and communicating the decision. Under existing OPTN Policy, a licensed psychologist, psychiatrist or master's level social worker can make the determination of capacity. However, to avoid conflict of interest, the clinicians performing the evaluation to determine capacity of the potential donors should ideally not be involved in the care of the intended transplant recipient to prevent a conflict of interest. Specific to persons with certain life-limiting illnesses, the informed consent process for living organ donation must: a) address potential peri-operative and post-operative risks, and b) be tailored to the specific situation of each potential living donor with life-limiting illness to ensure appropriate protections. Any revisions to the informed consent process, and peri-operative and post-operative care for living donors would require future public comment.

Withdrawal of Life Support After Donation

All living donors, as with all patients utilizing the healthcare system, currently have the right to refuse life-sustaining treatment (i.e., mechanical ventilation or ‘life support’). Accordingly, individuals with certain life-limiting illnesses also have the right to refuse life support after donation.

Do Not Resuscitate (DNR) Orders

If a potential donor with a life-limiting illness is approved for organ donation, the recovery hospital and the living donor should have clear documentation of the donor’s pre-, peri-, and post-surgical DNR status.

Transition from Capacity to Non-Capacity Prior to Living Donor Surgery

Living organ donation by persons with certain life-limiting illness must have the capacity to provide informed consent at the time of the donor surgery to proceed with donation.

Living organ donation by persons with certain life-limiting illness and plans for physician assisted suicide

The white paper does not include an analysis of living organ donation by persons with life-limiting illnesses prior to physician assisted suicide in this white paper.

Organ Euthanasia

Organ euthanasia is defined as the intentional removal of life-preserving organs in order to end a person’s life, and is prohibited by the Dead Donor Rule. Organ euthanasia is presently illegal in the U.S. and outside the scope of this paper.

Initiating a Discussion Regarding Living Organ Donation with Persons with Certain Life-Limiting Illnesses

Consistent with the usual practice with potential living donors without life-limiting illnesses, individuals with life-limiting illnesses should make the initial contact with the transplant hospital if they are interested in considering living organ donation. Medical professionals should not encourage such individuals with life-limiting illnesses to consider living organ donation simply because they have a life-limiting illness.

Case Examples of Potential Living Donors with Certain Life-Limiting Illnesses

The following case examples are provided as guidance on the option of living organ donation by persons with certain life-limiting illness. These examples are not intended to be exhaustive. For each example, individuals with certain life-limiting illnesses could be considered as a living organ donor if the individual:

- Meets the required criteria for the living donor medical and psychosocial evaluation,
- Provides informed consent for the donor evaluation and surgery,
- Would not be expected to have an undue risk of worsening the health status of the individual or hastening the death of the individual, as determined mutually by the transplant hospital and the living organ donor.

Progressive Neurological Diseases: Individuals with Huntington’s disease (HD), Amyotrophic Lateral Sclerosis (ALS), and Multiple Sclerosis (MS): Individuals with these

progressive neurological diseases could likely be considered as a living donor if the individual meets the criteria of the living donor medical and psychosocial evaluation, and the surgery would not be expected to unacceptably hasten the death of the individual.

Potential Donors with Advanced Chronic Obstructive Pulmonary Disease (COPD):

COPD is an inflammatory lung disease that results in obstructed airflow from the lungs. Individuals with chronic obstructive pulmonary disease may not be considered for living donation due to the increased risk for peri-operative complications and hastening of death with surgery. However, there is a wide range of disease severity and symptom burden such that living donation may be acceptable for some individuals.

Potential Donors with Pulmonary Arterial Hypertension (PAH): PAH is high blood pressure in the lungs and can lead to heart failure. Individuals with pulmonary arterial hypertension may also be acceptable as living donors depending on the seriousness of their disease and symptom burden.

Potential Donors with Cystic Fibrosis (CF): CF is an inherited disorder that results in severe damage to the lungs and digestive system. Individuals with cystic fibrosis may or may not be considered for living donation due to the increased risk for peri-operative complications and hastening of death with surgery. The severity of the disease will likely influence whether the individual with this life-limiting illness is an appropriate living donor.

Potential Donors with Non-Metastasizing Cancers, usually of the Central Nervous System: Individuals with non-metastasizing cancers, usually of the central nervous (brain and spinal cord) system may be appropriate living donors.

Potential Benefits of Living Organ Donation by Persons with Certain Life-Limiting Illnesses

Potential benefits of permitting living organ donation by persons with certain life-limiting illnesses include:

- Psychological benefits to the donor (e.g., providing improved self-esteem, providing enhanced meaning to one's life).
- Psychological benefit to the family or community of the donor, from knowing that their loved one was generous to other people prior to death.
- An increase in the number and quality of organs available for transplantation (i.e. a benefit to society).

Potential Harms of Living Organ Donation by Persons with Certain Life-Limiting Illnesses

Potential harms of living donation by persons with certain life-limiting illnesses include:

- The living donor's quality of life could be compromised as the donor may experience pain, or other complications that exacerbate their underlying life-limiting illness.⁵
- Living organ donation could hasten the living donor's death.

- Unintended effect on public understanding or trust in the transplant system.

By recognizing the potential harms for various stakeholders, transplant hospitals, and other regulatory entities may plan for mitigation of such consequences.

Recommendations

1. Transplant hospitals should consider individuals with certain life-limiting illnesses who express interest in living donation for living donor evaluation. That is, transplant hospitals should not automatically prevent such individuals from initiating the evaluation process.
 - Some elements of current OPTN Policies for living donor informed consent, psychosocial and medical evaluation and follow-up could be modified to accommodate the circumstances of individuals with certain life-limiting illnesses who wish to be living organ donors.
2. The OPTN should work with the transplant community, including patients and families, to determine if current policies for living donor informed consent, psychosocial and medical evaluation and follow-up are adequate and appropriate for individuals with certain life-limiting illnesses who wish to be living organ donors. If not, the OPTN could propose new additional requirements that would require and would be evaluated through future public comment.
3. Operationalizing and implementing the concept of living donation by persons with certain life-limiting illnesses will likely be challenging because of the concept's complexity. The OPTN could proactively identify ways to remove disincentives and to increase opportunities for living donation by persons with certain life-limiting illnesses, and refine assessment of transplant hospitals that undertake the recovery of organs from individuals with certain life-limiting illnesses who wish to be living organ donors.
4. The OPTN should engage in public and stakeholder education to inform potential clinical processes and ensure widespread understanding.

Conclusion

The autonomy of persons with certain life-limiting illnesses who want to be living organ donors should be honored and living donor transplant hospitals should be able to consider potential living donors with certain life-limiting illnesses without unreasonable regulatory consequence. Evaluation of any new related process or requirements needed in order to enable living donation by persons with certain life-limiting illnesses can be considered through future public comment