

The Role of the Independent Living Donor Advocate

What is it and why is it necessary?



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Independent Living Donor Advocate

The ILDA is a team member that is specifically assigned to work solely with potential donors. The ILDA role was developed in 2002 following the passing of a living liver donor. The Advisory Committee on Organ Transplantation and HHS advised that each institution will provide an independent donor advocate to ensure informed consent standards and ethical principles are applied to practice. They identified that this role

- Must function independently from the candidates team
- Advocate for the rights of the Living Donor
- Must be available to the donor from the beginning

Independent Living Donor Advocate

Goal of ILDA is to Assess 3 specific areas:

- 1) Motivation for Donation
- 2) Willingness and voluntary decision to move forward with donation
- 3) Understanding of the full process from evaluation to post donation



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Independent Living Donor Advocate Assessment

Motivation for Donation:

- What motivated them for donation?
- Are they here for a family member?
- Are they here for a friend or colleague?
- Are they here for someone they barely know?
- Are they coming to donate as an altruistic donor, meaning they wish to donate a kidney to someone they do not know at all?
- If they do know the recipient, we assess for any strains within the relationship. Could they be looking for any improvement or a change in the relationship?
- Are they looking for any publicity or significant recognition for this?

Understanding what brought them here and what if anything do they hope to get out of this experience. The significant majority of donors come in because they truly want to help someone and it's an amazing gift to be able to witness this on a regular basis.



Independent Living Donor Advocate Assessment

Willingness and Voluntary Decision to move forward with donation

One of the major areas of assessment is whether the person is here of their own free will and we attempt to ensure that there are no incentives, coercion or pressure to donate.

Questions to explore:

- Are they here of their own free will?
- Were they asked to do this? Or did they volunteer?
- Were they offered any payment or incentives to come here from the recipient or the recipient's family?
- Do they feel like they have to and there is no way out of it?
- Do they feel that this is the best decision for them at this time?



Independent Living Donor Advocate Assessment

- Within families, there can be external pressure such as someone saying “you need to do this for the recipient” or there can be internal pressure within the donor “I am their only family member and I feel like I have to do this for them even though I might not want to”. So we assess whether this is an expectation or personal motivation?

And if they are here not of their own free will, do they understand that we can provide them with a medical out and that this can be kept confidential?



Independent Living Donor Advocate Assessment

Donor's Understanding of the Process

Lastly the donor advocate needs to ensure that the donor has received information and education in the following areas as well as assist them in obtaining additional information if requested

- Informed consent
- Evaluation process
- Surgical procedure
- Medical risks
- Psychosocial risks
- Follow up requirements with the benefit and confirmation that they will make every effort to complete those post donation check ups so that we can ensure they are doing as well as they should be

ILDA meets with the donor's after they have met with every discipline to review what they have heard, allow time to process and confirm that with receiving all of this information, they still wish to proceed with donation.

Independent Living Donor Advocate

After the Evaluation:

ILDA confirms the donor knows how and why to reach out to this role and confirm they understand that the ILDA is available throughout this continuum of care process.

The ILDA will then meet or speak with the donor prior to surgery to again confirm their continued comfort level and offer an opportunity to talk about some potential fear or anxiety surrounding surgery if any.

ILDA then plans to see the donor in the hospital after surgery and then again post discharge to provide support and assess for any concerns.



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