

Navigating Complex Family Dynamics in Living Donor Liver Donation: Speedbumps Are Not Always Stop Signs

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14th Annual Living Donation Conference

Presented by the American Foundation for Donation and Transplantation

“Ideal Donor”

- No medical or psychiatric contraindications
- No financial concerns/strong financial support plan
- Adequate health literacy- “did their homework”
- Firm and simple motivation- ex: the “no brainer”
- Intact and supportive family system



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Family Dynamics in Living Donation

- Limited research on family dynamics and their impact on living donor motivation and informed consent when donating to a family member (pertaining to US population)
- Current literature does not adequately address specific ways for centers to evaluate and consider donors who may want to donate to a family member with whom they have a complex or distressed relationship



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Bias

- Bias may be towards donors with uncomplicated or traditionally “good” relationships with family member recipient candidates
- May be missing out on the opportunity to complete further assessment or offer additional support in order to allow donors with more complex situations to proceed



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Creates Limits on:

- A center's ability to help recipient candidates
- A program's commitment to the value of donor autonomy



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Case Study

- Offers an example of how our team approached the evaluation and support of a donor in a distressed family system while prioritizing:
 - Donor Autonomy
 - Informed Consent
 - Donor Safety



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UPMC Process

- Potential donor submits information through our website
- Nurse coordinators screen donors based on criteria (age, BMI, health history, etc)
- ILDA team contacts donor for pre-evaluation conversation
 - Review process, screen for coercion or pressure, discuss medical out
- Evaluation
- Post-Evaluation Follow Up
 - Assess understanding of process and risks



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Living Liver Donor: First Evaluation

- Donor evaluated for donation to his biological parent
 - Metastases to the liver from a non-liver primary cancer
- Male, early 40's, married, two children
- Deemed a good medical and surgical candidate
 - Minimal alcohol use, remote rare drug experimentation, quit nicotine the prior year
 - No psychiatric contraindications
- Confirmed caregiver (wife)
- Self-employed
- Lives in a different state from our center
- Donor described his relationship with his recipient as “distant” but intact



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Approved But Delayed

- Donor was approved and surgery was scheduled
- Surgery was then cancelled due to medical issues in the recipient
- A little over one year later, recipient was deemed eligible again
 - Donor once again came forward to donate



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Second Evaluation

- No changes to donor's health status, caregiver plan, finances, or psychiatric history
- However...
 - Donor disclosed that he and his recipient had a serious falling out and were no longer on speaking terms
 - Donor reported his sibling had considered donating instead because of this rift but the sibling changed their mind
 - Donor expressed a strong desire to avoid any contact with his intended recipient at any point during the donation process
 - Our team had concerns about how this dynamic would impact donor's ability to proceed safely



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Essential Areas of Assessment

- Motivation
- Informed Consent
- Pressure or Coersion

Multiple Timepoints

- Before Evaluations
- Evaluations
- After Evaluations
- ILDA team following this donor closely throughout



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Motivation

- Donor's motivation was assessed thoroughly by ILDA team, nurse coordinator, social work, and psychiatry
 - First Evaluation- Donor reported that he wanted to help his parent live a longer life
 - Second Evaluation- Donor felt strongly that he wanted to donate because he believed it was the right thing for him to do for himself and his value system
 - Exercise in forgiveness
- Donor denied expectations that donation would improve his relationship with his parent or change it in any way.
 - This was a particularly important assessment point during the second evaluation
- Donor denied experiencing any pressure to donate from his intended recipient or other family members at all time points.



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Informed Consent

- Donor was educated on risks of living liver donation and endorsed full understanding
- Donor was provided additional information related to transplant as a treatment of liver metastases via living donation and outcomes
- Discussions were held with the donor about stressors that could occur that were unique to his situation
 - No guarantee that he would not encounter his recipient while inpatient or during follow up
 - Informed donor that some of his specific requests (such as being on a separate unit from recipient immediately post surgery) were not feasible
 - Complications or poor outcome for himself or recipient may be more difficult to process



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Extra Support for Donor

- ILDA team offered to assist donor find therapy resources
- ILDA team discussed with donor strategies for navigating communication between donor and recipient prior to surgery should he desire it (such as a family meeting with a moderator or other neutral third party)
- Precautions were arranged by the medical team to minimize the chance of contact
 - Room assignments on opposite ends of transplant units
 - Extra briefing with inpatient staff
- Multiple inpatient post-surgery contacts to offer support and assess coping



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Outcome

- Donor was approved
- Recipient was agreeable to proceeding
- Transplant was completed
 - Donor did report unintended contact with the recipient on more than one occasion prior to arriving at the hospital for surgery
 - No additional conflict was reported
- Donor endorsed having a positive experience with donation immediately post donation and during multiple follow ups



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Take Aways

- While donor evaluation is in many respects “one size fits all”, much of it is also “case by case”
 - Unanticipated situations often require flexibility and creativity
 - Anticipate speedbumps
 - Standardized guidelines should be partnered with clinical judgement
- When in doubt, more conversations are better
- Teamwork
- Meeting donors where they are whenever possible
 - If we can do it safely, we should strive to let donors make the call



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Special thanks to all the living donors who give the gift of life



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Thank you

