

Transplant
Institute



Beth Israel Deaconess
Medical Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Finding a

Living Liver Donor

How to Discuss Living Liver Donation

Needing an organ to sustain your life is not something that happens every day, nor is asking someone to donate a portion of one of their own organs. It is understandable you may have trouble knowing where to start. We hope this brochure will help you.

Things to consider when trying to find a living donor

- Tell friends, family and acquaintances about your liver disease, treatment options and the alternative of live donor liver transplantation. Educating people who know you is one of the most important steps in finding a living donor, and discussing the facts can be less stressful than asking for a living donor.
- Communicate in way that is comfortable for you, using group or individual meetings, or by letter, email or social media like Facebook.
- While you may feel burdened making such a significant request of a friend or family member, keep in mind that they may feel similarly burdened watching the effects of your illness on your quality of life. Living donation may not only help you, but also help your family and friends feel useful.
- Select a "champion" – a family member or friend who is willing to talk to others about living donation for you.
- Give potential donors time to consider their options. Some people can decide quickly, while others need more time to weigh the risks and benefits to make their decision. Pressuring potential donors may discourage willing donors.
- Reassure potential donors that their decision will not affect your relationship. For some prospective donors, as much as they may want to help you, donation may not be the right choice.
- While you cannot offer potential donors money or other rewards of monetary value for donating, you may assist with expenses associated with the donor process such as travel, parking, meals, child care or lost wages if this is within your financial capability.

Who can be a living donor?

A donor may be a family member, friend, co-worker, acquaintance, neighbor, work colleague, church contact, or someone you have not previously known. Optimal donors have excellent general medical and emotional health and volunteer to donate free of coercion, pressure, or financial gain. Liver donors must be between the ages of 18-55 and must have a compatible blood type with their intended recipient.

Live Liver Donor Myths & Realities

MYTH	REALITY
Only a blood relative can donate to me	You do not need to have a blood relationship to someone to receive a liver transplant from them.
Only someone with my blood group can donate to me	A living donor needs to have a compatible blood type, but not necessarily an identical blood type. Which blood types are compatible are dependent on your blood type. In addition, anyone can receive a liver from a blood group O donor; (they are the universal donor).
Potential donors need to live in New England, or near Beth Israel Deaconess Medical Center	While living liver donor evaluations need to be performed at BIDMC, out of town donors will be considered. Given the donor's need to travel, an efficient donor evaluation can be arranged. The surgery is performed at BIDMC and the donor is asked to stay locally until their first post-operative appointment.
Donors need to take medications after donation for the remainder of their lives	Living donors require medications for the first several weeks after donation surgery. This is only a temporary need.
Female donors cannot have children after liver donation	Female donors are able to have healthy pregnancies after donation. It is recommended that pregnancy be postponed for 1 year after donation.
Members of the Transplant Team may pressure someone to be a living donor	Donors are free to change their mind about donation at any time during the evaluation process. Donors will not be responsible for letting the recipient know if they choose not to donate.
Being a living donor is expensive	The recipient's insurance policy is responsible for expenses related to the donor evaluation, hospital care, and related follow up care.
The Donor Team will update me about my donor's progress in their evaluation	The donor evaluation process is confidential. Only your donor can share their information with you. The Donor Team is not able to speak directly with you.
Only 1 donor should self-refer for consideration as a living liver donor	Anyone interested in considering living donation is encouraged to call the donor coordinator to learn about the donation process and complete a health history. The Donor Team will review all donor candidates to determine who is best suited to complete the donor evaluation.

Blood type compatibility

DONOR	RECIPIENT
A	A, AB
B	B, AB
O	O, A, B, AB
AB	AB

How have other BIDMC patients identified living donors?

- Family
- Friends
- Friends' relatives
- Neighbors
- Work colleagues
- Facebook and social media
- Email sent to contacts
- Through the work of a champion/advocate

What if one of my children wants to consider living donation?

It is not uncommon to feel conflicted about accepting a liver from an adult child. Adult children often offer donation after appreciating how chronic illness has affected their parent's quality of life. If your children are considering living donation, keep in mind that the Donor Team will carefully evaluate their suitability to be a living liver donor and that living donation is a safe option for them. The most important Donor Team responsibility is to advocate for the donor's best interests at all times with an emphasis on the safety of the living donor.

Why would someone want to donate a portion of their liver? What's in it for them?

Donors are amazing people who are motivated to help for a variety of reasons. Sometimes they have had a personal experience with illness in a family member or friend which motivates them to donate. Sometimes donors are familiar with liver disease and aware what an amazing difference live liver donation can make in the life of the recipient. Sometimes donors are motivated by altruistic ideals or compelled by religious tradition and faith. While donors do not experience a medical benefit from donation, the vast majority of them experience an emotional benefit. When asked years later, most donors report being very satisfied with their decision to donate and identify donation as one of their proudest moments, comparing it in importance to significant career accomplishments, long term marriages or relationships, and successful parenting.

The Donor Experience

Potential donors receive extensive education about donation during their evaluation and have multiple opportunities to ask questions about donation from highly experienced nurse coordinators, social workers and physicians. Here's a general description of what donors can expect in uncomplicated situations:

- Thirty to forty five minutes to complete a telephone health screening
- Comprehensive consultations and testing which occur over several days
- Evaluation process may take 6-8 weeks
- Formal review of a donor's candidacy by the Donor Team
- One half-day of pre-operative appointments approximately one week before donation
- Hospital admission the day prior to surgery
- Hospital stay of 5-7 days
- Eight to 12 weeks of recovery
- After recovery, donors can return to any normal activity, including sports

How to begin the conversation

Different communication strategies may work for different people depending on your relationship and your comfort level discussing your health issue. You may wish to consider some of the following conversation starters:

- "Asking for someone to consider liver donation is very difficult. I know this conversation is awkward for both of us."
- "My doctors recommend living donor transplantation as the best treatment option for me."
- "I want you to take time to think about this. Don't be afraid to ask me questions."
- "I don't want you to feel pressured so I won't bring this up again. Living donation is a big decision which will involve some sacrifice on your part. It is okay for you to say no. I won't be offended or hurt if you choose not to consider living donation. I recognize that saying no does not mean that you don't care about me or love me."
- "While living donation is a better treatment option for me, it is not the only option. I am also on the deceased donor waiting list as well as talking with other potential living donors."

Using Social Media to Find a Donor

The internet is an easily accessible way to share information quickly with a large audience. Many patients who are looking for a living donor consider using social media websites like Facebook, Twitter, LinkedIn, or YouTube to make profiles or videos. Before you decide to use the internet as way to find a potential living donor, it's important to weigh the risks and benefits of doing so.

Pros of Using Social Media

- Increases awareness among people you know about your end stage liver disease and need for a liver transplant.
- Widens your search; you can reach many people, including some you don't know.
- Increases the efficiency of your search; you can message friends and followers instantly.
- Social media communication might be more comfortable for you than face to face discussion.
- Your website or social media page provides others with information about you, which can lead to wider relationships and a larger support network for you.

Cons of Using Social Media

- Once your personal information is posted, it is out of your control.
- There is a risk of disappointment if you don't receive the response you are hoping for.
- You risk victimization by exposing yourself to people who could try to take advantage of you. One way they might do this is by expecting payment, gifts, or relationships in return for their liver donation.
- Although you will reach a lot of people through social media, many of the prospective donors you reach will not be candidates for donation due to medical, social, or mental health concerns. This influx of donor inquiries can impact the Donor Team's ability to respond efficiently to potential donors.
In our experience, only 5% of potential donors reached through social media end up qualifying to donate compared with 25% reached through more traditional ways. This can be disappointing and frustrating to you and your family.

If you decide to post your health information, here are some general recommendations

- Stay positive on your website. It may help you to cope, while also managing other people's impressions.
- Consider asking your champion/advocate to manage your online profile for you. They can write from their own perspective.
- Share educational information about liver disease.
- Offer information on living donor eligibility (as provided by the BIDMC Transplant Institute).
- Tell a compelling, interesting story in order to increase interest. For instance, talk about why you are motivated to get a transplant. Talk about how this disease has affected your life and how you have coped with it.
- Actively maintain the page with frequent posts and updates in order to keep followers engaged.

Next Steps

Once you are listed for a liver transplant, your donor candidates can reach out to the living donor nurse coordinator, Denise Morin, RN at **617-632-9717** to begin the process with their Donor Team of clinicians.

Helpful Websites

www.livingdonorassistance.org

www.transplantliving.org

www.unos.org