

- State that they should contact one of our Living Donor Coordinators if they want to have an informal discussion of the process before deciding to move forward.
- Let them know that the donor evaluation is confidential— you will not know if they choose to be evaluated to be a donor and will not participate in the evaluation process.
- Let them know that your relationship, both now and in the future, is not based on their response.

Things to consider before asking

Considering how varied your relationships may be, you might choose to practice with your transplant or dialysis social worker, or someone with whom you've already had the donation discussion. Who and where will you ask? Should you talk with certain people in private? Should you hold the conversation in a large group so no one feels pressured? How will you ask? Will you hold one-on-one conversations, send a group letter or email (written by you or another family member) or hold a one-time group conversation? When should you ask? Would it help to have this announced at work or at your church/religious organization? It may be helpful to set aside a special time for this conversation. Holidays or other family celebrations may not provide the best opportunity to have a serious conversation.

To Learn More

If anyone is interested in learning more about the option of living kidney donation, they should contact the Tulane Transplant Institute at East Jefferson and ask for the Living Donor Coordinator. The coordinator will be able to review the process with them and provide a copy of our Living Donor booklet, if they have not already read it. You may also go to our website at ejgh.org/tulanetransplant. Additional information can be found at LivingDonorsOnline.org. Many potential donors find it very helpful to hear from someone who has been a donor. The Living Donor Coordinator can put you in touch with living donors who are willing to speak with potential donors about their experiences.



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East Jefferson
General Hospital
LCMC Health



How to begin the conversation about living kidney donation



East Jefferson
General Hospital
LCMC Health



Living kidney donation

The number of patients on the waiting list for a deceased donor kidney transplant continues to rise. There are not enough deceased kidney donors for everyone who is in need of a kidney transplant. An option for many patients is a kidney from a living donor. The benefits of living kidney donation and detailed information about the evaluation and donation process are described in *Everything You Need To Know About Living Kidney Donation*. The purpose of this pamphlet is to help you with the difficult process of letting your friends and family know of your need and giving them a chance to help you.

For many families, the opportunity to help a loved one who is ill or having surgery is limited to sitting by the bed side, helping prepare food, helping with household chores and perhaps helping take care of children or spouses. Living kidney donation is a very special circumstance where family and friends can actually do something to truly help you – they can help save your life. We encourage you to give your family and friends this opportunity to help you live a better and longer life with them. Everyone may not be suitable for donation but they want the chance to try to help you. Consider that they may be very upset if you exclude this possibility for them to help you in such an amazing and courageous act.

We understand this is a difficult thing to do, but here are some pointers on what to consider before you have the conversation and how to begin the conversation.

Before you ask

It is important that you explain the full extent of your condition to your family and friends. Irrespective of the living donor option, it is crucial to engage their support and understanding during your illness. It is impossible to go through the transplantation process on your own. You risk a worse outcome if you try to “go it alone.” You will likely need help with many of your daily activities after the transplant, for a period of time.

Consider gathering everyone together to discuss your condition and your treatment options which include living kidney donation. Your transplant social worker and your transplant coordinator are always available and willing to help you understand your disease process and the treatment options. To help you with this, we have provided in written form most of what was discussed with you during your evaluation.

If you feel uncomfortable or nervous about trying to explain everything to your family and friends yourself, members of our team will be happy to help with this conversation. Having this conversation with your family and friends is not just about living kidney donation but it also is an opportunity for them to volunteer to help you in many other ways during what may be a very long illness and recovery time.



Be prepared for the associated emotions

Chronic illness such as kidney failure and dialysis can be very draining both physically and mentally. You may be struggling with a full spectrum of emotions ranging from anger, anxiety, and depression. As you read this, you may also be experiencing emotions such as guilt, fear, anxiety, and pride as you think about telling family and friends about your need for a kidney transplant and the very long wait ahead of you for this life saving gift. These are all normal emotions under the circumstances, but also consider what your family and friends may be feeling— helplessness, fear, anxiety and depression. They may be wishing and hoping

there is something they can do to be more helpful to you in your recovery. Do not deny them that opportunity.

Fear and concern for the health and safety of your family and friends, should they decide to be a donor, is real and is a perfectly normal reaction. However, it is our responsibility and that of our Living Donor Team to make sure it is safe for your donor to donate. Under no circumstances would a donor operation be performed if this team felt there was a significant risk to the donor. Their primary concern is the health, safety and wellbeing of the potential living donor.

When your family and friends learn of your need for a kidney transplant, they may immediately think about living donation.

Remember, they are struggling with the same wide range of emotions as you are and now they may feel ashamed that they don't want to donate, or angry that you are reluctant to accept their offer to donate a kidney. You will work through these emotions on your way to building your support team and we— “Your Team for Life”— are here to help you through this very difficult time.

How to begin the conversation

Make a few clear statements during the conversation to help reduce tension and eliminate confusion.

- You do not expect or want anyone to offer to donate that day— you want to merely explain your condition and the available treatment options to them. You want to allow your family and friends time to thoroughly consider their answer and not respond based on emotions alone.
- State that you will not ask or bring up the topic again. Let them know they can contact you for more information and give them a copy of the brochure *Everything You Need To Know About Living Kidney Donation*.