

Staff Guide:

Facilitating Donor Outreach Conversations with Patients

- The following guide is meant as a general overview for having donor outreach conversations with recipients. It provides some ideas on how to explore donor outreach and things to address.

1. Purpose of Conversation: Introduce the subject of finding a living donor and why living donor transplants are the best treatment options.

- “Today I wanted to talk about ways to find a living donor. It’s important because we know there are better health outcomes with a living donor transplant and so it’s important to consider this option.”
- “I’m hoping we can touch on living donor transplant and finding a donor today. I want to chat about it not only because it’s the best treatment option for renal disease, but when you have a living donor you are able to have your transplant sooner and avoid waitlists.”

2. Understand Patient’s Experience of Donor Outreach

- “Have you ever let people know about your need for transplant to see if they’d be willing to be a donor for you?”
- “Have you ever tried to find a living donor?”
 - If Yes:**
 - “Tell me about how you did this” or “How did you go about getting your message out?”
 - If No:**
 - “What holds you back from reaching out to others?” or “What stops you from doing donor outreach?”

3. Identify and Address Any Barriers: Understand what makes them hesitant to do outreach and provide relevant information to help them with their discomfort. Some examples of barriers and responses below:

Worry for Donor’s Health:

- “Many recipients are concerned for their donor’s health. While there is a small risk with donation, the majority of people live long, healthy lives with just one kidney.”
- “Donors are thoroughly medically screened to make sure it is safe to donate. The transplant teams are cautious with donor health, and the donor’s long term health is carefully considered.”

Uncomfortable To Ask:

- “I can understand why you would feel that way. It’s important to know that many donors offer to donate once they understand the medical need. You don’t need to ask for a kidney donation, you can let them know about your medical situation and invite them to explore donation if they are interested.”
- “Try to shift your thinking from asking for a kidney donation to communicating your medical need, and making an invitation to others to get more information if they are interested. We know donors often will take the next step once they understand the need for transplant.”

Worry About Feeling Indebted:

- “Donors often say they don’t want recipients to feel indebted to them and want things to remain the same in their relationship with the recipient. Donors are equally concerned nothing changes in the relationship.”
- “Donors often say they see donation as a gift. They are focused on helping the recipient because they care about them and say that the donation has no strings attached. Donors want things to continue normally after donation.”

No One To Ask:

- “Did you know that your donor doesn’t have to be a family member or the same blood type? Even if you have small social circles, just letting a few people know about your situation can be enough. It just takes one person to step forward.”
- “Remember a donor can be someone you knew in school, worked with, or be part of a group or church you have belonged to. If someone in your family or a friend is willing to communicate your message to their own social circles, it widens your network of possible donors. We know that when donors have even a small connection to a recipient, donors will step forward.”

Cultural Barrier:

- “I appreciate and want to be sensitive to your cultural values/belief.... (Choose one of the following)
- “I’m wondering if you can think of a way we could make transplant an acceptable medical option for you without you compromising your cultural beliefs/faith. Is there some way to bridge the two?”

- “Would there be any thing that could be done so that your culture is honoured but still allow you to be transplanted?”
- “I’m aware of an Indigenous gentleman who was able to receive a transplant after his Band Chief gave him permission. Would something like this be available to you and how would you feel about that?”

Out Of Country Donors:

- “Yes, it is possible but there can be challenges which lengthen the process. Visitor Visas can be difficult to get approved and can take time. Donors must have access to health care once back in their home country. They must have the same blood type as you. You can have those donors contact the pre-transplant team and they can begin the process. We still encourage you to look for a donor here because it is easier to screen someone in Canada, and usually faster.”

4. Assist With Outreach Message: Find out how the recipient likes to communicate and provide information on crafting the message.

- “What way of communicating feels comfortable to you when you think about letting others know about your medical situation? Do you prefer to speak directly with people, write a letter or email, or use social media?”
- “Try to think of your message as having a beginning, middle and end. The beginning let’s people know you are in need of a kidney transplant and a few facts about living donation. The middle can be reassuring people about your relationship if they don’t step forward, and you can let people know of any of your concerns related to them hearing

your outreach message. The end is making an invitation for people to explore donation if they are interested, and providing the contact information for the transplant centres.”

- “If you write a letter or email I’d suggest you address it as “Dear Family and Friends” not just to individuals. This helps people reading your message not to feel singled out.”
- “Let recipients know some basic facts about kidney donation, like donors can live long healthy lives with just one kidney, and they are not obligated to proceed with donation if they change their mind.”

5. Assess How Recipient Feels About Donor Outreach At End of Conversation:

- “How are you feeling about doing donor outreach now?”
- “Do you think you will try to do some outreach now?”

If Yes:

- “Here are some resources to help you as you begin. There are also more resources on the BCT and BCPRRA website or you can call me if you’d like some more help.”
- “Here are some resources to help you with your outreach. Feel free to call me if you need some help or find you get stuck along the way.”

If No:

- “It’s okay if you don’t feel ready yet. Maybe give it some thought and we can touch base about it again when we meet.”
- “Okay, I don’t want you to feel pressured in any way. Why don’t we leave it for now and let’s touch base about it when we meet next. You’re always welcome to call me if you change your mind or if I can help in some way before then.”