

Conversations With Patients About Donor Outreach

This document provides helpful strategies to talk about kidney donation and donor outreach with patients who are potential candidates for a transplant (check with the patient's nephrologist to confirm appropriateness of transplant for individual patients and document response). It highlights information about the kidney donor process and ideas for talking with patients about ways to find a donor and share their story.

Talk to patients about benefits of living donor kidney transplantation

Learn about kidney donation and the transplant process. It's a good idea to learn as much as you can. The following are some helpful resources:

Key talking points about Living Donor Kidney Transplant (LDKT)

- Transplantation is the best therapy for most patients with end stage kidney disease because it provides the best quality of life and helps people live longer compared to dialysis.
- Living donor kidney transplantation is the best therapy for most patients because it offers the quickest access to transplantation and it results in the best outcomes after transplantation (living donor kidneys last longer than deceased donor kidneys).
 - Receiving a kidney from a live donor helps avoid a long wait for a deceased donor. Refer to [transplant](#).

bc.ca/data/median-waiting-time-months-first-adult-deceased-donor-kidney-transplants-blood-type for estimated wait-times for deceased donor transplantation based on the ABO type and sensitization history.

- A successful kidney transplant can be as much as triple a patient's life expectancy. For patient and graft survival rates, refer to [transplant](#).
bc.ca/search?search_api_views_fulltext=kidney%20donor&type=All
- Goal is to identify potential living donors and have them worked up and ready for when the transplant is needed by the patient. Generally patients are transplanted when their GFR is between 10 and 15. It may be earlier if the patient is symptomatic.
- Patients who receive a kidney transplant require ongoing medications, monitoring and follow-up for their entire life. This care is coordinated by Post-Transplant Clinics located throughout the province. Essential components include lifelong anti-rejection medication, regular blood tests and ongoing communication with the clinic including clinic visits.

Key Talking Points about Living Donors and Processes

- The goal of donor outreach is NOT to pressure family and friends to donate, but to educate them about the impact that kidney disease has on people's lives and to provide the opportunity to donate

if they wish.

- Living donation can be very safe and kidney donors go on to live normal lives with one kidney. Living donors must be in good health and have normal kidney function.
- Donors are thoroughly medically tested to be sure it's safe for them to donate. Donor safety is a priority.
- The donor's medical information is kept confidential by the donor team.
- Donors do not have to be a blood match or be related to be able to donate.
- If a donor is not a match for the potential recipient, donation may be possible through participation in the national paired exchange program.
- Start donor outreach early. If an approved donor is identified, the timing of the transplant is optimized for most recipient benefit. The recipient is notified that an approved donor is available:
 - For recipients ready for transplant, notification is provided after the donor confirms his/her willingness to set a surgery date.
 - For recipients not ready for transplant, notification is provided after the donor confirms his/her willingness to donate once recipient is read.
 - Other accepted donors are not notified that another successful donor has been located until after the transplant has occurred.
- Surgical procedure description- see video by Dr. Gourlay: [youtube.com/watch?v=DsLq-jJ1vLM&t=1377s](https://www.youtube.com/watch?v=DsLq-jJ1vLM&t=1377s)

Empower patients to be informed about transplant

Websites	<ul style="list-style-type: none"> • BC Transplant: transplant.bc.ca • The Kidney Foundation of Canada, BC Branch: kidney.ca/bc • Canadian Blood Services: organsandtissues.ca • National Kidney Foundation (USA) - excellent recipient and donor testimonials: kidney.org/transplantation/livingdonors
Resources for patients	<ol style="list-style-type: none"> 1. <i>Finding a Donor: Getting the Word Out</i> (booklet) <ul style="list-style-type: none"> • Available in English, Punjabi & Chinese • Information for patients on how to go about finding a donor. • Download it at: transplant.bc.ca/livingdonation (click on Live Donor Kidney Program, then Finding a Donor) 2. <i>Step-by-Step Guide for Kidney Transplant Recipients</i> (booklet) <ul style="list-style-type: none"> • Available in English, Punjabi & Chinese • Download it at: transplant.bc.ca/health-info/organ-transplant/kidney-transplant (go to Resources, click on Step by Step Guide through the Kidney Transplant Process) 3. Introduction to Kidney Transplant: A Step by Step Process (video) <ul style="list-style-type: none"> • Content is similar to the guide above but provides more details, including information about living donors. • Watch it at: youtube.com/watch?v=mKEHbyzjxnU
Resources for learning more about living donation	<ol style="list-style-type: none"> 1. <i>Living Organ Donation: Let's Learn More</i> <ul style="list-style-type: none"> • Information about the importance of kidney donation and how to become a donor. • Download it at: kidney.ca/britishcolumbia/brochures (Under Resources, Organ Donation) 2. <i>Step-by-Step Guide for Living Kidney Donors</i> (handout) <ul style="list-style-type: none"> • Available in English, Punjabi & Chinese • About becoming a living donor and the process. • Download it at: transplant.bc.ca/livingdonation (click on Live Donor Kidney Program, then The Living Donor Transplant Process) 3. Living Kidney Donation: A Step by Step Process (video) <ul style="list-style-type: none"> • Content is similar to the guide above but provides more details. • Watch it at: youtube.com/watch?v=cYAc-HqBgmo 4. Living Donor Expense Reimbursement Program (LODERP) <ul style="list-style-type: none"> • LODERP can help donors with some of the travel and accommodation costs related to assessment and donation. • kidney.ca/britishcolumbia/loderp

Talking with patients about starting a conversation about living donation

Assure recipients that the subject of living donation isn't an easy conversation to start and it is common to feel uncomfortable asking someone to consider donating a kidney.

Counsel patients that it may be difficult to even think about accepting such a big gift, but encourage patients to be mindful that potential donors are screened carefully to ensure that they are healthy enough to donate and they are doing it for the right reasons.

Talk to patients about ways to reach out to family, friends or others about kidney donation. Encourage patients to share their situation with people they know and to tell them what it's like to live with kidney disease. Empower patients to be open and honest about their situation and feelings.

Talk to patients about how it is difficult for people to offer to help if they don't understand their situation and what they are going through. Help recipients focus on the positive aspects of their outreach efforts.

Reassure them that your relationship with them will not change whether they step forward or not.

Examples of ways patients can reach out to potential donors

1. Have conversations directly with others.

2. Write letters or e-mails (see section 6 for information about a donor outreach letter/e-mail template)
3. Use Facebook as a platform or other forms of social media. Caution about risks of doing this and address ways of doing it safely.
4. Empower patients to ask a friend or family member to be a "donor champion" for them to help get the word out about kidney donation. Encourage patients to keep their advocates informed about their health.

Getting the word out – supporting patients

Encourage patients to share their story with friends and family first. Patients can branch out to broader social networks like church, community organizations or others if needed afterwards. By getting the word out, patients may be fortunate enough to have offers from people who are willing to be tested or want more information.

It may be difficult to even think about accepting such a big gift, but keep in mind potential donors are screened carefully to ensure that they are healthy enough to donate, they are well informed and they are doing it for the right reasons.

Speak to patients about using technology and social media like Facebook. Caution patients about the risks of public solicitation. Encourage patients to do outreach in their immediate circles first and speak about how donors are likely to come out of conversations with friends or relatives over

people attracted through public solicited campaigns.

Possible Ways to Start the Conversation with Patients

- Have you ever thought about talking to friends, family about kidney donation?
 - **Yes-** Can you tell me about what happened?
 - **No-** What holds you back? Maybe we can talk about ways to make this easier for you.

Encourage exploration of living donation before ruling it out completely.

What recipients can tell potential donors

Counsel recipients to let potential donors know that exploring kidney donation is not a commitment to move forward and they can back away from it at any point. Tell them that potential donors can speak with a transplant coordinator at Vancouver General or St Paul's Hospital confidentially to gather additional information about the process. Reassure them that the donor team and recipient teams at Vancouver General and St Paul's Hospital are separate to ensure confidentiality is maintained.

Encourage recipients to reassure people they are reaching out to that their relationship with them will not change whether they step forward or not.

Donor outreach letter/email template: What is it and how to use it?

A sample letter/e-mail that includes key talking points about kidney donation is attached. It is a platform for patients to be honest, open and genuine with people and share that they have kidney failure and need a transplant.

Encourage patients to personalize the template to fit their own story and share information that is important to them and that they are comfortable telling others. They can include details about their medical situation and how kidney failure affects them such as, their symptoms, how it impacts their daily life, and their current medical treatment.

Counsel patients that there may be a delayed response from anyone they may have sent the outreach template to. Encourage patients to give them time to process the information. Speak about how patients may also not get a response from those they send it to. Counsel patients on sharing their story and letting it go without expectation of a response.

Donor outreach plan

Donor outreach is about making a plan for who to reach out to and how best to reach them.

Developing the plan may include three steps:

1. Identify people/groups to approach.
2. Think about all the ways to reach each of group and decide what might work best.
3. Choose which group(s) to approach first.

Encourage patients to develop a donor outreach plan and suggest they start by talking to those closest to them. If unsuccessful, suggest branching further out in their social circles or using other strategies to share their story (see section 3).

Some patients find it useful to think about their “social circles” in a picture format and use it as a way to think about what groups to approach and what order would be best. Refer to the patient information sheet on Donor Outreach: Finding a Donor and Talking about Kidney Donation for an example.

Donor team resources

Staff with questions about living donor transplantation, eligibility, etc may contact the Living Donor Teams at either:

1. Vancouver General Hospital by phone at 604-875-5182/1-855-875-5182 or by email at kidneydonornurse@vch.ca; or
2. St. Paul’s Hospital (Vancouver) by phone at 604-806-9027/1-877-922-9822 or by email at donornurse@providencehealth.bc.ca

References:

- kidney.org/transplantation/livingdonors/how-to-make-the-ask (National Kidney Foundation)
- lkdn.org/advantage_pre_emptive_tx.html (LivingKidney Donors Network)
- transplant.bc.ca (BC Transplant)