### **Patient Teaching Tool**



# Finding A Donor And Talking About Kidney Donation



This guide includes resources for patients about kidney transplant and for people who may be interested in becoming a living kidney donor. It also talks about ways for patients to share their story to help them find a donor.

#### **Get informed first**

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

Helpful Resources for Patients and Potential Donors	
Websites	<ul> <li>BC Transplant: transplant.bc.ca</li> <li>The Kidney Foundation of Canada, BC Branch: kidney.ca/bc</li> <li>Canadian Blood Services: organsandtissues.ca</li> <li>National Kidney Foundation (USA) - excellent recipient and donor testimonials: kidney.org/transplantation/livingdonors</li> </ul>
Resources for patients	<ol> <li>Finding a Donor: Getting the Word Out (booklet)</li> <li>Available in English, Punjabi &amp; Chinese</li> <li>Information for patients on how to go about finding a donor</li> <li>Download it at: <a href="https://www.transplant.bc.ca/health-info">www.transplant.bc.ca/health-info</a>. Click on Living Donation.</li> </ol>
	<ul> <li>Step-by-Step Guide for Kidney Transplant Recipients (booklet)</li> <li>Available in English, Punjabi &amp; Chinese</li> <li>Download it at: <a href="https://www.transplant.bc.ca/health-info">www.transplant.bc.ca/health-info</a> Click on Kidney Transplant.</li> </ul>
	<ul> <li>Introduction to Kidney Transplant: A Step by Step Process (video)</li> <li>Content is similar to the guide above but provides more details, including information about living donors</li> <li>Watch it at: <a href="mailto:youtube.com/watch?v=mKEHbyzjxnU">youtube.com/watch?v=mKEHbyzjxnU</a></li> </ul>





## Resources for potential donors

- 1. Living Organ Donation: Let's Learn More
  - Information about the importance of kidney donation and how to become a donor
  - Download it at: <u>kidney.ca/britishcolumbia/brochures</u> Under Resources > Brochures > Organ Donation.
- 2. Step-by-Step Guide for Living Kidney Donors (handout)
  - Available in English, Punjabi & Chinese
  - About becoming a living donor and the process
  - Download it at: <a href="www.transplant.bc.ca/health-info">www.transplant.bc.ca/health-info</a> Click on Living Donation.
- 3. Living Kidney Donation: A Step by Step Process (video)
  - Content is similar to the guide above but provides more details
  - Watch it at: <a href="youtube.com/watch?v=cYAc-HqBgmo">youtube.com/watch?v=cYAc-HqBgmo</a>
- 4. Living Donor Expense Reimbursement Program (LODERP)
  - LODERP can help donors with some of the travel and accommodation costs related to assessment and donation
  - <u>kidney.ca/britishcolumbia/loderp</u>

### Starting the conversation

Bringing up the subject of living donation isn't an easy conversation to start. It is common to feel uncomfortable asking someone to donate a kidney.

Think about ways you can share your story.

#### Examples of ways to share your story:

- Having conversations directly with others.
- Writing letters or e-mails (see page 3 for information about a donor outreach letter)
- 3. Consider using Facebook as a platform

- or other forms of social media. Speak to your social worker about ways to do this safely.
- Consider asking a friend or family member to be a "donor champion" for you and help get the word out about kidney donation.

If you feel uncomfortable about starting outreach, you can contact your renal social worker or transplant team social worker to assist you to work through these feelings and receive support.





#### Getting the word out

Share your story with family and friends first. You can branch out to broader social networks like church, community organizations or others if needed as well.

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 they can speak with a transplant coordinator confidentially and can gather additional information about the process.

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

# Sample donor outreach letter: What is it and how to use it

A sample letter with key talking points about kidney donation is available at <a href="https://www.transplant.bc.ca/health-info">www.transplant.bc.ca/health-info</a>. The letter is a way for you to be honest, open and genuine with people and share that you have kidney failure and need a transplant.

You can personalize it to fit your own story and share information that is important to you and that you are comfortable telling others. You can include details about your medical situation and how kidney failure affects you such as your symptoms, how it impacts your daily life, and your current medical treatment.

### Things to consider

There may be a delayed response from anyone you send the outreach letter to. Give them time to process the information. You may also not get a response from those you send it to. Kidney donation is not the right fit for everyone so if some of your social network does not step forward, it's not a reflection on you or your relationship with that person.

Donors often step forward and offer to donate once they understand the medical need. They do not need to be asked.





# People considering living donation might like to know

- 1. Donors live healthy, normal lives with one kidney.
- Donors are screened carefully to make sure they are medically okay to donate a kidney.
- The donor assessment process is confidential. Donors can gather information and be assessed before making a commitment to donate.
- Donors must start the screening process themselves by contacting the Living Donor Team at Vancouver General Hospital or St Paul's Hospital. See contact information on page 5.
- 5. At any step in the process, a prospective donor can choose not to proceed with the donation.
- 6. The Living Donor Expense
  Reimbursement Program (LODERP)
  can help donors with some of the
  costs related to assessment and
  donation, including time away from
  work: kidney.ca/britishcolumbia/
  loderp.

\*Source: Finding a Donor: Getting the Word Out (handout) transplant.bc.ca/patients/kidney-transplant

#### **Donor outreach**

Donor outreach is about making a plan for who to reach out to and how best to reach them. It might be helpful for you to break it down into 3 steps:

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

When you start thinking about your donor outreach plan, a good place to start is with those you feel closest to. If these conversations are unsuccessful, you may then want to branch out further into other social circles or use other strategies to share your story.

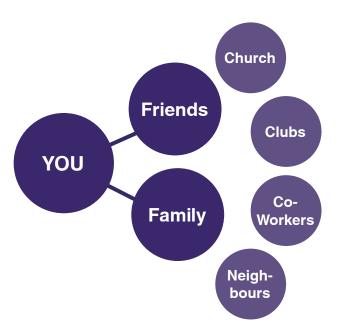
Some groups that other patients have found helpful to talk to include but are not limited to:

- Family and friends
- Co-workers
- Neighbors
- Church
- Recreational clubs





Some people find it useful to think about their social circles in a picture format. Your picture will look different than the one below because everyone's social circles are different. But it might be a way for you to think about what groups to approach and what order would be best.



#### **Donor team information**

If a potential donor has expressed interest in donating a kidney, ask them to contact the Living Donor Teams:

- 1. Vancouver General Hospital by phone at 604-875-5182/1-855-875-5182 or by e mail 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













