

How to Talk About Living Kidney Donation with Family and Friends

For people with kidney disease and their loved ones: this pamphlet contains information shared by kidney transplant recipients and donors about living kidney donation in the hopes that it will help you feel comfortable sharing your story and finding a living donor.

Share your story!

Achieving the healthiest possible you takes effort. You will need information. Ask many questions. Learn as much as you can. Be your own advocate. Share your story. Let your friends and family help you.

It is never too early to start talking to your family and friends about your kidney journey. If you have chronic kidney disease (CKD), tell your friends and family about your kidney journey even if you hope that you will never need a kidney transplant.

You may be surprised that people are interested in learning about what you are going through. You will find that if you simply share your story, some people will ask how they can help. Some may also be interested in becoming your living donor. If people express an interest in helping, you can tell them living donation is an important option and share the name and number of your Living Kidney Donor Program.

You can get your Living Kidney Donor Program's information from your healthcare team or the [Trillium Gift of Life Network website](#). The people who come forward may not be who you expect. Many living donors are not related to the person with kidney disease.

“Stay strong. Stay positive. Never give up. There will no doubt be hard days; there will be good days too.”

-Susan M.

Here are a few key facts that can help you talk to your friends and family about transplant:

A kidney transplant from a living donor is the best treatment for many people with kidney failure.

It is better to have a transplant before or very soon after starting dialysis to avoid health problems related to being on dialysis.

While transplants from both living and deceased donors can greatly improve and extend life, research shows it is better if the kidney transplant comes from a living donor. Living donor kidney transplants tend to last longer than deceased donor transplants and may even help you live longer. Recipients of living donor kidney transplants tend to get transplanted sooner and have more time and energy to do the things they enjoy.

It may take up to a year or more to explore if a person can be your donor.

Even with the best treatments, your kidneys often slowly wear down. You might never know exactly when you will need to start dialysis. It can take a year or more for your donor to complete the required medical tests and see several medical specialists to determine if they can go forward with donation. That is why it's so important to think about living donor kidney transplant and talk with potential donors early in your journey, ideally before you know for sure you will need a transplant and at least a year before you may need to start dialysis.



Ontario Health
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A person interested in learning about being a living kidney donor should call their [Living Kidney Donor Program](#) as soon as they are ready to find out basic information.

You will also need to go through your own detailed testing to be approved to receive a kidney transplant and that process can take up to a year.

Living kidney donors usually recover quickly.

Living donors have to be healthy to pass the medical tests to be a donor. Because they are healthy, living donors can usually get back into their normal routine within three months of the surgery. The living donor process ensures kidney donors are well informed and carefully evaluated – that is part of the reason why it takes so long. Many living kidney donors find their experience to be deeply rewarding because of the feelings of happiness, satisfaction and relief that come with seeing someone they care about have much better health after their transplant.

Visit transplantambassadors.ca to learn more about the Transplant Ambassador Program (TAP) and also ask if you can connect with a transplant recipient or living donor at your next clinic appointment.

Some of the donor's costs may be covered.

The Ontario government may pay for some of the donor's expenses through a program called [PRELOD – Program for Reimbursing Expenses of Living Organ Donors](#). This can include some of the costs for travel, accommodations and lost wages. The donor will have to pay for the expenses up front and apply to the program with receipts to get some of the money back.

If a donor isn't a match for you, they may still be able to help.

If your living donor is not a good match for you, they may be able to take part in [Canada's Kidney Paired Donation](#) program. The Kidney Paired Donation program is a "kidney swap" where you will get a matching kidney from another donor. Your donor's kidney will go to another person in need and your kidney will come from someone else in the program.

A transplant can be a good option for older patients.

There is no age limit to receive a kidney transplant as long as you're healthy enough. New advances in treatment mean that kidneys from older donors can now be safely transplanted later in life with great success.

Social media has become a common tool for finding living donors.

If you are active and comfortable on social media, share your story on those platforms (e.g., Facebook, Instagram, YouTube, etc.). Using social media can help you reach many people at the same time and there are many examples of people with kidney failure who have found their donor on social media.

While social media is a great tool for sharing your journey with others, keep in mind that you may not be able to control with whom and how your story is shared.¹

Always remember: you, your families and your friends deserve the healthiest possible you.

People who express an interest in being a donor usually do so because they care about your well-being and it is hard for them to see you suffer. You may be surprised who is interested in finding out more about being a donor. A kidney transplant can be a life changing experience for both a person with kidney disease and for a kidney donor.

You are not alone!

You can speak to living donors and people who have received kidneys through the Transplant Ambassador Program (TAP). The ambassadors understand what you are going through. They have joined TAP because they want to help you. You can visit transplantambassadors.ca for more information about TAP. You can also ask at your next clinic if they can connect you with a transplant recipient or living donor.

Additional Resources:

For more detailed information on the criteria for donating a kidney or the PRELOD program, please see [Trillium Gift of Life Network's website](#).

To find additional resources for you or your donor, visit ontariorenalnetwork.ca/transplantationresources

¹ Transplant hospitals will not share or endorse social media posts from potential recipients looking for a living donor.

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