



# Having Your KIDNEY Donor Find YOU!

## Developing Your Story and Elevator Speech

As you know, developing your story is the central theme to your kidney campaign and the most effective way for your donor to find you. Here are three main goals that you want to achieve when developing your story:

- Convey the situation you are in
- Develop an emotional connection
- Describe how someone can be of help

The most important thing is for your story to be authentic and for it to be from your heart. This is how you'll make a memorable connection that will motivate someone to learn more and ultimately take action.

Here are some important things to include:

- Describe your current condition
- Briefly explain how you got to this point
- Mention what you've done so far to stay healthy or the health challenges you are facing
- Describe what might be unique about you and your situation
- Include a fact or two about why you are pursuing a living donor, i.e. the wait for a deceased donor could be 5-10 years or a kidney from a living donor lasts twice as long as one from a deceased donor, or you want to see your children get married, have grandchildren or some other life goal you have.
- End by letting them know that the way they can help which is to share your story or how they could be tested
- If you are telling someone your story verbally it's often helpful to ask if you can send them some additional information as a follow-up
- If your communication is written, you should include:
  - Your contact information
  - The link to the Having Your Donor Find YOU! website.
  - Contact information of the living donor coordinator and/or the center's website. (Always get the center's prior permission to include the donor coordinator's information.)
- Put in your own personal touches as appropriate.

Developing your story is similar to writing a cover letter for a job search. Your goal is to connect with someone so they are motivated to share this with others or consider donating themselves.

As an example, here is my story:

Dear \_\_\_\_\_,

This is a letter I never thought I'd be writing 5 years after my kidney transplant and 4 years after launching the Living Kidney Donors Network...especially after helping so many recipients and kidney donors through the transplant process.

I've had some challenges with my transplanted kidney, and **I need to have another kidney transplant.**

The transplanted kidney my wife donated to me in 2007 enabled me to live a full and rewarding life for these years, but it has been damaged as a result of the virus I contracted. While the virus is rare, patients who have had this virus do well when re-transplanted.

Other than this virus I've been staying in good shape, working out regularly, eating healthy and regularly monitoring my kidney tests.

I will be going on the kidney transplant waiting list for a deceased donor kidney, but it's far more beneficial for me to pursue a living kidney donor. The main reasons for this are that the deceased waiting list is over 5 years and the kidney from a living donor lasts on average twice as long as a deceased donor. Also, if at all possible, I would like to avoid going on dialysis, which can be debilitating.

Let me tell you a few key points about kidney transplants:

- Organ donors need to be in good health, without high blood pressure, kidney, heart, liver or other major health issues. It's not so much about someone's age, as it is about their health that determines their suitability. Having the same blood type is not a major issue to overcome.
- The new anti-rejection drugs have made "matching" of donor/recipient much easier. If the donor/recipient are not compatible, kidney paired exchange programs allow these donors to be paired and matched with other incompatible pairs
- All medical expenses are paid by the recipients (my) insurance company. It is legal for the donor to be reimbursed for any lost wages, travel or post-transplant care expenses that they might incur.

If you or others would like to learn more about the donation process, please contact me or the living donor transplant coordinator to discuss it in detail.

I would really appreciate it if you can pass this information along to your family members and/or friends who might be interested in learning about my situation.

Thanks very much for your support and concern for taking time to learn more.

All the best,  
Harvey

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As we've discussed, it's important to abbreviate your full story so you can convey this to more people as the opportunity arises. This is called an Elevator Speech. Here is more about that process.

### **The Elevator Speech**

The elevator speech is a quick summary of your longer story that you developed. It's named for the time it takes for a short ride in an elevator, roughly 30 seconds or less. Strive to make this crisp, concise and compelling.

You, (and your advocates,) can use your elevator speech when someone says, "Hi, how are you?" After you or your advocate responds with "Kidney Campaigning" they'll likely want to hear more and it's the perfect time to use your elevator speech. (I like the 'Kidney Campaigning' response because it gets someone's attention quickly. You can also just say "I'm OK, but you might not know that I'm in need of a kidney transplant", and then proceed with your elevator speech from there).

Remember to stay focused on the most important message you want others to remember. You can end the conversation by telling them how appreciative you'd be if they could please share your story with others. You might even ask them for their email address so you can provide them with more information or hand them one of your business cards.

Keep in mind that you don't always have to be prompted with someone saying, "hi, how are you" to give your elevator speech. Opportunities present themselves all the time at grocery stores, coffee shops, an Uber ride, almost anywhere. Many recipients have met their donor in these types of situations.

Not everyone makes the decision to donate or help someone the first time they learn about it so staying in touch opens that opportunity for them in the future.

Take some time and give some thought to your elevator speech. It should feel natural, authentic and sincere. It may not feel comfortable the first few times you tell someone your elevator speech, but it will get better, especially if you practice. Make changes to it if it doesn't feel right. If you get emotional, just pause for a moment, people will understand. That pause

might reinforce the importance of your need and help others connect closely with your situation.

Here is the Elevator Speech I used to communicate my need:

You may not be aware, but I've had some challenges with my transplanted kidney and I need to have another kidney transplant. The transplanted kidney my wife donated to me in 2007 enabled me to live a full and rewarding life for those 5 years, but it has been damaged as a result of a virus that attacked my kidney.

I will be going on the kidney transplant waiting list for a deceased donor kidney, but it's far more beneficial for me to pursue a living kidney donor. The main reasons for this are that the deceased donor waiting list is over 5 years and the kidney from a living donor lasts on average twice as long as a deceased donor.

I am spreading the word as broadly as possible because I'm motivated to have a living donor transplant.

(If the conversation continues, here is some additional information I was prepared to discuss:)

- Organ donors need to be in good health, without high blood pressure, kidney, heart, liver or other major health issues. Age and blood type are not major issue to overcome.
- Living Kidney donors do not have to be related.
- Matching donors/recipients has become much easier due to anti-rejection drugs. In addition, if the donor/recipient are not compatible, paired exchange programs allow these donors to be paired and matched with other incompatible pairs.
- All medical expenses are paid by the recipients (my) insurance company. If needed, donors could be reimbursed for lost wages or any travel expenses incurred.

I would appreciate it if you could please share this message with your family members and/or friends who might be interested in learning about my situation.

Thank you so much!

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As you can see it all starts with composing a clear, concise and authentic message so others understand your situation and know what they can do to help. Once you have the full story in mind (and on paper), you can trim it back to the essential points for communication with others in your day-to-day life.

You can also share your story via an email to a group of family and friends. This might not come across as warm and personal as an in-person conversation but it lets you share your need with

many people quickly. I urge you to follow-up with conversations to those you've written so you can reinforce the importance of your need and answer any questions they might have.

This is all about helping your donor find you, so develop a communication plan that fits your style and personal community.