



Dave, kidney transplant recipient

Overcoming Common Kidney Donation Myths

MYTHS (FALSE)	FACTS (TRUE)
<p>✗ The donor will have many out of pocket expenses.</p>	<p>✓ The medical costs are covered by the recipient's insurance. People can apply for grants to help with uncovered costs.</p>
<p>✗ Once a donor begins the donor evaluation process, that person may feel obligated and afraid to change her or his mind.</p>	<p>✓ A donor can change their mind at any time.</p>
<p>✗ My religion prevents me from being a donor.</p>	<p>✓ Most religions support living donation.</p>
<p>✗ If a person does not offer to donate, that must mean the person is not interested in donating.</p>	<p>✓ Many people don't know that living donation is an option.</p>
<p>✗ A donor will have trouble getting health insurance/life insurance after s/he donates.</p>	<p>✓ There are protections in place to ensure donors have appropriate access to care.</p>
<p>✗ Living kidney donors won't live healthy lives with just one kidney.</p>	<p>✓ Donors are carefully screened to ensure they are healthy and can have a nephrectomy. They are encouraged to have regular checkups and follow a healthy lifestyle.</p>
<p>✗ Living kidney donors live a shorter life.</p>	<p>✓ There is no evidence that donation shortens a person's lifespan.</p>
<p>✗ Living kidney donors are more likely to get kidney disease after donating.</p>	<p>✓ Donors are counseled about their individual risk associated with donation.</p>

NEED MORE INFORMATION?

NKF Cares Help Line
855.653.2273
nkfcares@kidney.org

NKF Peers Support Program
855.653.7337
nkfpeers@kidney.org



MYTHS (FALSE)

- ✗ Only younger people should be able to get kidney transplants.
- ✗ Adults over age 50 can't donate.
- ✗ Those with tattoos and LGBT people can't be living kidney donors.
- ✗ A kidney donor can no longer participate in sports or exercise.
- ✗ Kidney donors will have to take medications for the rest of their lives.
- ✗ A kidney donor will have debilitating pain for an extended period of time.
- ✗ A kidney donor will be in the hospital for an extended period of time after surgery.
- ✗ Living kidney donors don't get to choose to the person who gets their kidney.
- ✗ A donor will have to follow a new diet plan following donation.
- ✗ A donor can no longer consume alcohol following donation.
- ✗ A female donor should not get pregnant after donation.
- ✗ A donor's sex life will be negatively affected by donation.

FACTS (TRUE)

- ✓ All patients who are medically suitable are eligible for transplants.
- ✓ Donors must be healthy and can donate primarily on a basis of health, not age.
- ✓ All donors are medically screened and for infectious diseases, such as hepatitis, and are only cleared if it is safe for both the donor and recipient.
- ✓ A donor should be able to return to regular activities and exercise about 4 to 6 weeks after surgery.
- ✓ Generally, prescriptions for pain and stool softeners will be necessary only in the immediate postoperative period.
- ✓ Ordinarily, there will be some pain after surgery, which will diminish and can be controlled with pain medication.
- ✓ A kidney donor will be hospitalized, on average, for 2 nights.
- ✓ A donor can select a person they know.
- ✓ A donor should eat a healthy, well-balanced diet, but there are no dietary restrictions
- ✓ While excessive alcohol use is always dangerous to one's health, a kidney donor can consume alcohol in moderation.
- ✓ A female donor should wait to become pregnant until medically cleared after donation.
- ✓ Donors may engage in sexual activity when they feel well enough to do so.

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National Kidney Foundation®



Starting My Story

The key to finding a living donor is **sharing your story** —as a kidney patient, family member or friend. This worksheet is designed to help you develop your story that you can share widely. Be as honest as you can, as your answers here will not be shared with anyone. Then you can use this as a “jumping off point” for creating a written story that you can share.

Here are some ideas of what your story could include:

1) Introduction

- Your first name & connection to kidney disease. For example:
 - “My name is Alex and I have been waiting for a kidney transplant for 4 years.”
 - “Hi, this is Jennifer and I’m writing because my uncle Marc needs a kidney.”

2) More Details

- Include some personal details about the kidney patient (whether that’s YOU or you’re writing about a FAMILY MEMBER or FRIEND):
 - When diagnosed, how long on dialysis, how long waiting for a kidney
 - What’s difficult about kidney disease, dialysis, and/or waiting for a transplant
 - Hobbies, interests, pets, passions, close family members or friends
- What’s involved in being a living donor
- See the “Sample Stories” in your packet for ideas.

3) Conclusion

- How a transplant would help, would it improve the patient’s life
- If people are interested in donation, what should they do? (Give contact information for the transplant center or who they should reach out to)
- Other ways that people can help by spreading the word, etc. (See the “Sample Stories” in your packet for ideas)

My Story

In the space below, start writing some ideas/thoughts about what you could include in your story.

Introduction

More Details

Conclusion



Sample Stories

Here are some examples of **actual stories shared by kidney patients and families** through social media, emails, community newsletters, and other channels.



For those who may not know, I was born with Polycystic Kidney Disease (PKD). I inherited it from my father, who was in his early 60s when PKD took his life. In late 2015, right after my 1 year wedding anniversary, my doctors told me that it is time to start my transplant journey.

Many of you know that I'm not one to openly share my private life. As much as I want to fight the good fight on my own, it's no longer realistic without the help of others. For the sake of my family—particularly my lovely wife, I am reaching out for your help.

I am searching for a living donor. I am also on the kidney transplant waiting list but the wait is long. My blood type is O+. You can help me fight this fight in several ways:

1. Spread the word to your family and friends who might know someone who is willing to serve as a donor. You can start by simply sharing this message on Facebook.
2. Prayers and positive support are always welcome and much appreciated.
3. It is not my place to outright ask you for your kidney—that is a very powerful and personal gesture -- however, I would be truly grateful for such a selfless gesture.
4. You can learn more about donation from the National Kidney Foundation at www.kidney.org/transplantation/livingdonors.

I don't make these requests lightheartedly. I simply want to extend my time on this Earth to continue to explore new avenues of my career, enjoy my still young marriage with the love of my life and expand our family unit, enjoy watching my nieces and nephew grow up, and--if it is not too much to ask for--watch my beloved NY Rangers win at least one more Stanley Cup--now I know that I'm asking for too much right!?

Thanks for reading this message!



Alex, the son of **Mike Reed '76**, is in need of a kidney transplant. The doctors say that a living donor organ would give Alex the best outcome because of his young age.

THE GIFT OF LIFE

We recently received a very important request. In the month of October, when the focus is on the Respect for Life, this request has pertinent meaning. *(Name)*, a member of Saint Alexis Parish, is in critical need of a kidney transplant. He suffers from unexplained end-stage renal disease. He has been approved for a transplant, but this is only the beginning of what might be a very long process. He is in need of a living kidney donor. A living donor is ideal in that it expedites the transplant process since the wait time on a donor list is currently 3 to 6 years. Besides, a living donor significantly improves one's survival rate.

To be a kidney donor, you need to be in generally good health. Routine tests are performed to determine the potential donor's viability. Kidney donors go on to live long healthy lives with one kidney. All costs incurred by the donor are covered by Medicare. The average recuperation time in the hospital is two to three days and two to three weeks at home.

To learn more about becoming a live kidney donor, call the transplant hospital at *(phone number)*.

Thank you for your serious reflection on this topic and taking the time to learn more about it. In the meantime, let us immediately begin praying for *(name)* and anyone in his situation who is waiting for an organ transplant. Know that you and the members of your family are being remembered in our prayers.



Jeff, kidney transplant recipient

Are you interested in learning how to find a living kidney donor through telling your story?



Write up a few sentences (or paragraphs) about your situation. Include key points that will help people understand your life with kidney disease. Try including how your life has changed since you received your diagnosis and if you've started dialysis. Share how transplant, especially living donation, can give you your life back, allowing you to return to work and enjoy family time again.



Once you have your story written, you can share it anywhere or with anyone with whom you feel comfortable. Some ideas include: sharing your story with your friends, family members, social media connections, coworkers, place of worship, and community groups that you belong to.

If you are a family member or friend of a kidney patient, you can help share their story too, using the same key points as above. Just be sure to get the patient's permission before sharing their story!

The key is to ask people to continue sharing your story in their own circles, too. The more you share your story, the greater your chances of having a living kidney donor come forward.

Find sample letters that other patients have shared at:
[kidney.org/livingdonation](https://www.kidney.org/livingdonation)



Patients and family members can create a Facebook page and continue to regularly post updates on your transplant journey. By doing this, it will keep people involved and will allow them the opportunity to share your story with others, while also giving them a chance to make an informed decision about whether to consider donating a kidney to you.

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Conversation Starters

Opening the Conversation:

- "I would like to talk to you about something important. Let me know when you have time to chat."
- "I wanted to let you know that I have kidney disease. I've been waiting for a kidney for about 2 years now."
- "You know my cousin, John? He has kidney disease and is on dialysis, which is a huge burden to him. He is waiting for a kidney transplant and was told it will take approximately 8-10 years unless he finds a living donor."
- "I was told I'm not able to donate a kidney for Sue so I am trying to spread awareness about her need for a kidney. I am hoping that sharing her story might inspire someone else to possibly donate a kidney to her."

Conversation Points:

- "Dialysis is a huge burden and makes John's life much more difficult."
- "The doctors say that a kidney transplant from a living donor is the best treatment option."
- "Did you know that you can live a healthy and complete life with just one kidney?"
- "The evaluation to be a kidney donor is very thorough and paid for by the recipient's insurance."
- "The transplant team won't let you donate unless they determine you are healthy at the time of donation."

Closing the Conversation:

- "Thank you for listening and for having this conversation with me. If you have any questions, please don't hesitate to ask."
- "I appreciate that you let me speak to you about this. It truly means a lot that you're even considering the option of being a donor and/or willing to learn more".
- "Please share this information with anyone you think may be interested in getting evaluated or learning more."



Tips for Using Facebook

Creating Your Page

1. Go to: www.facebook.com/pages/create.php
2. Click on the "Cause or Community" category.
3. Consider sharing your story (or your loved one's story) in the "About" and "Description" sections:
 - Describe the patient's life now and how a transplant could help
 - Describe the kidney patient and who they are (for example: family, work, friends, hobbies, activities, goals)
 - Share contact information and/or link for initial screening tool for the transplant program and coordinator
 - Make it as easy as possible for people to make contact by including names, phone numbers and e-mail addresses if you have them

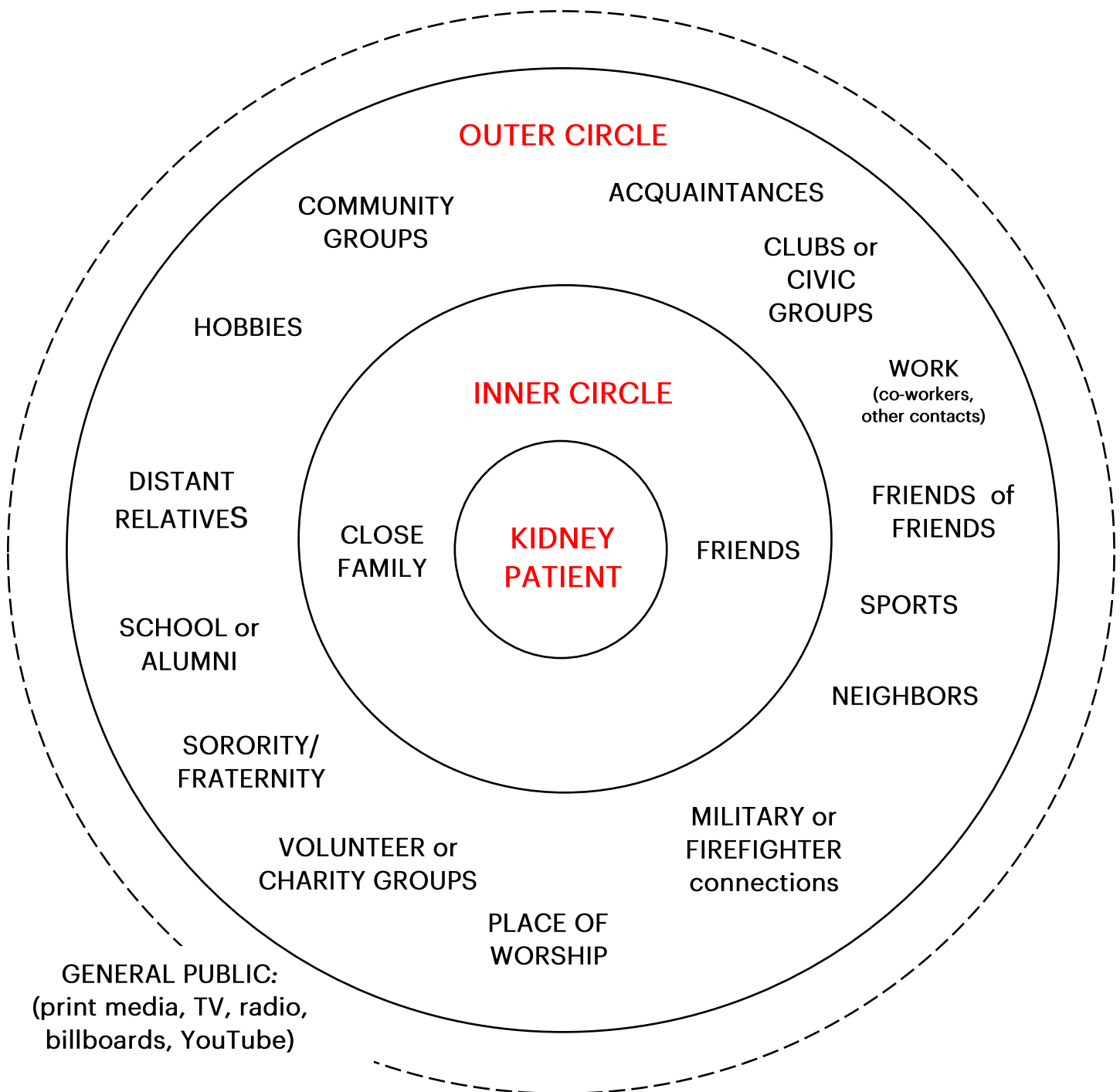
Share Your Page

We suggest making this a "closed page" and sharing it with your friends and friends of friends on Facebook only

- Post a link to it on your personal Facebook page and ask others to "like" and "share" it. (Not everyone knows how to do this, so be sure to say something like "Click the words 'like' and 'share' directly below.")
- In addition, post your link on the Living Kidney Donor Search Page on Facebook.
- Two or three times a week, post status updates, pictures, or general donation information to keep those who have liked your page interested. However, keep it to 2-3 times a week; if you post too many times, people will no longer notice your posts. They may even "unlike" your page to avoid receiving so many posts. Share the link with everyone you know who is on Facebook or willing to join. E-mail is also an excellent way to spread the word to those who aren't on Facebook.



Circles of Influence



My Circles of Influence:

Who might consider donating? Who could help spread the word? List as many **individuals** and **groups** below as you can. Think about your personal connections, and those of other family members or friends (*for example, Bob, high school classmates, Janet's Tuesday knitting group*).

Close Family:

Distant relatives:

Friends:

Neighbors, Acquaintances:

Co-Workers:

School/Alumni groups:

Place of worship:

Recreational groups:

Sports teams:

Community groups:

Volunteer or charity groups:

Clubs or civic organizations:

Hobbies:

Other:



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My Action Plan

Name: _____

What do I commit to doing next?	I will:	I will find someone to:	By when?
Finish writing my story using the "Starting My Story" worksheet.			
Share my story on social media – Facebook, Instagram, and/or Twitter. <i>(Please see the handout on setting up a Facebook page.)</i>			
Share my story by email or letter to my <i>Circles of Influence</i> .			
Create a flyer or business card to hand out to my <i>Circles of Influence</i> .			
Find social gatherings to talk about the story.			
Use newsletters or bulletins to share the story.			
Set up a blog or web page about the need.			
Create a video about the need.			
Use community media <i>(Note: talk to the transplant center for advice first).</i>			
Talk to people using the "Conversation Starters".			
Build a Network of Advocates. I'll reach out to at least 5 people to share what I've learned today and ask them to help spread the word: 1. _____ 4. _____ 2. _____ 5. _____ 3. _____			
Ask the transplant center for more information about donation.			
Contact NKF Cares with questions. (855.NKF.CARES/ nkfcares@kidney.org)			
Ask NKF for a Peer mentor . (855.NKF.PEER/ nkfpeers@kidney.org)			
Learn more on the NKF website at www.kidney.org/livingdonation .			
Join NKF's Online Communities . (https://healthunlocked.com/nkf-kidneytransplant and https://healthunlocked.com/nkf-donors)			
Help others by signing up as an organ, tissue and eye donor at www.registerme.org .			
Other actions:			