

How to use social media to help you find an organ donor

One of your biggest challenges is finding a suitable donor. The good news is that a living donor does not have to be a relative. It can be a friend, coworker or spouse. It might also come from an altruistic, nondirected organ donation, in which individuals donate to a recipient that they do not have a relationship with.

Facebook

Facebook can be a valuable tool to help raise awareness for your cause among people you know, as well as friends of those people. If you are not familiar with Facebook, use this step-by-step guide to help you use this valuable social media tool.

Step 1 | Create a personal Facebook page

If you don't already have a personal Facebook page, you will want to create one.

1. Go to www.facebook.com.
2. Complete the sign up form and submit.
3. You will then receive an email or text message from Facebook to confirm your account.
4. After you've set up your page, you can begin requesting friends. Type names in the search bar to find family and friends you know and trust and click **Add Friend**.
5. You will need to decide whether you want this page to be private or public. If it is private, only people whom you are "friends" with will be able to see your page. If it is public, people whom you don't know will be able to see your page, which might be beneficial as it expands the community of people who may see your page and decide to donate.

Step 2 | Create a group Facebook page

If you don't want to use your personal Facebook page in your search for an organ donor, you can create a group Facebook page specifically for the purpose of finding a donor. We recommend you use both for optimal results.

1. Go to the top right corner of your personal Facebook page, click the down arrow and select **Your Groups**.
2. Then select **Create Group** on the right margin of the page.
3. Fill in your group name, people whom you want to add to your group and then choose the privacy setting for your group.
4. Click **Create**.

Step 3 | Create a memorable group page name

1. Log into your group page and click the ellipses (...) located in the top right corner of the page. Select **Edit Group Settings**.
2. Scroll down to web address, click **Customize Address**.
3. Enter a customized address for your group page so that it can be found more easily. Then click **Customize Address**.

Step 4 | Create your first Facebook post

1. Go to your Facebook page and click **Create Post** in the top left hand corner of the first box of your news feed.
2. When you create your first Facebook post, you'll want to explain your situation and create an emotional appeal. Here's an example of a first post that you can personalize as needed:

Our family has recently been faced with a huge health care challenge. My father, Bob, who has been dealing with chronic kidney disease for the last several years, has received difficult news. He needs a kidney transplant. My dad is hopeful and determined to beat this. Unfortunately, there is not nearly enough kidney organ donors to accommodate the number of people who need a kidney, so we are looking to find individuals who might be interested in being a living donor by donating one of their kidneys. Believe it or not, you can live and function quite normally with just one kidney. If you are found to be a match, you would literally be saving his life. If you or someone you know are interested in learning more, please private message me or see this list of **frequently asked questions** at <https://www.NebraskaMed.com/Transplant>.

Follow the instructions below to post your first photo.

3. Add a photo: Always try to include photos with your posts of you and your family and friends throughout your journey as they will draw more interest to your posts. Videos may boost your engagement another notch and can add more emotional appeal.

To add a photo, click **Photo/Video** under the body of your text. Click on the folder that contains your pictures and double click on the photo you'd like to post. If you want to post more than one photo, click **Photo/Video** again until you've added all of your photos. You can also drag your photos into the text box.

4. When you have completed your post, click **Post** at the bottom of the box.
5. If you need to edit your post after it has posted, click on the ellipses (...) on the top right corner of the post and click **Edit Post**.

If you'd like to create your own post, use this checklist to make sure you cover important elements in your post.

1. **Opening**
Express your desire to explain your challenge and reassure the potential donor that he or she will not need to make a decision because of it.
2. **The who**
Explain for whom you are making the request.
3. **The what**
Briefly explain the medical condition that is making the transplant necessary.
4. **The why**
Describe why a transplant surgery is required.
5. **The when**
A sense of urgency should be incorporated into your message. You should also indicate how much time a living donor would need to invest.

6. The closing

Ask potential donors to take time to think about this decision and provide ways for them to contact you to discuss or get more information.

Step 5 | Create update posts

You'll want to provide routine updates, perhaps once a week or once a month depending on how fast things are moving. If you post more than that, it may become overwhelming.

Remember to keep your posts short. Ideally, they should not be more than 250 characters. Under 80 characters is even better. Below is an example of what your second post may look like. Here are some examples of several update posts.

2nd post

Hello everyone!

We want to thank all of you for your support and for staying in touch. It really means a lot to our family. My dad is hanging in there and in good spirits, but we are still in search of a compatible living donor. We have had several friends get tested, but unfortunately, they were not matches. Please reach out if you might be interested in being tested or learning more.

Life event posts

To keep your friends engaged and to show them that your loved one is living a fruitful life, include updates on events and personal experiences about your life and everyday activities happening in his or her life. Share stories of how others have been there for you, no matter how big or small the help has been. Remember, always keep your posts positive and encouraging to keep everyone's hope and spirits up.

Here's an example of what one of those posts might look like:

It was a great day today! We celebrated my dad's 68th birthday. It was a wonderful celebration and all four of us kids were there to spend this special day with him. We are still hopeful that we will be able to find a living donor. We appreciate any assistance in helping us make that happen! That would be the best birthday gift of all!

Found a donor post

Great news! A match has been found for my dad. Thank you all for all of your love and support over the past several months. We are so excited about this awesome news. It looks like his surgery will probably take place next week. We will keep you all updated about the surgery and his recovery. Please keep us in your prayers.

Step 6 | Share and like other posts

Whenever possible, "share" or "like" the stories of others who are looking for a living donor and they will likely share yours as well. Don't hesitate to share someone else's post, and then privately reach out to see if they'll share yours. To share or like, click on the **Share** or **Like** icons under their posts.

Step 7 | Reply to posts

Show your appreciation to those who share or respond to your posts or are helping your find a donor in other ways. When someone posts a reply to one of your posts, you can click **Like** or **Reply** under their response and thank them for their support.

Step 8 | Tag others in your pictures

Tags others in your pictures so they can see your story too. To tag others, slide the cursor over a person's face who is in the picture. A text box will appear. Type their name in the box and click return.

Step 9 | Use a frame on your profile picture

Encourage friends to use it as well. [Here are instructions.](#)



Other social media outlets

Other social media platforms that you may want to consider using include YouTube, Twitter, Instagram and Snapchat. Facebook is most popular among the 18 to 54-year-old age group, which is the ideal age range for a living donor. The use of hashtags is another social media tool you may want to use to help spread the word.

Security recommendations

Since this is going on the internet, you will want to be selective as to what you share. Avoid these things when posting on any type of social media:

- Personal phone numbers
- Residential addresses
- Personal email addresses
- Family information
- Any other information that might be considered sensitive
- Posting images while you're out of town
- Inappropriate photos

Other resources you might find helpful

CaringBridge

CaringBridge is an organization that allows you to set up your own website so you can easily communicate your health journey to family and friends. To begin, visit <https://www.caringbridge.org/>, register and follow the instructions.

Live On Nebraska

<https://liveonnebraska.org/>

The Center for Organ Recovery & Education (CORE)

[CORE.org](https://www.core.org/)