



## Pursuing a Living Kidney Transplant Getting Started Suggestions

There are many reasons why someone who is in need of a kidney transplant does not pursue a living kidney transplant. The two most common obstacles are, not knowing all the facts about living donation and apprehension about asking someone to donate. Learning about living kidney transplants is the first step to success, second is to develop a clear message letting other people know about your need. The more knowledge you have about living kidney donation, the more likely you'll be willing to discuss your need with other people.

Kidney donation is a Gift of Love, and Gifts are given, not asked for. Every donor/recipient story is unique. However, when polled, donors say that they offered to donate after hearing about their family member or friend's situation. However, someone who might be willing to donate is unable to do so unless they know about your need.

### Developing Your Game Plan

1. Learn as much as you can about the living kidney donation process. The more you know about living kidney donation, the easier it will be to talk about your situation.
2. Form a team of people that will help you. The more people helping you achieve your goal the better your chances are of being successful. If you are not prepared to be the team leader, a family member or friend could help.
  - a. Personal Advocates – Friends and family members that will help spread the word about your need.
  - b. Medical Advocates – Someone who will be with you during your medical appointments.
  - c. Medical Team – Doctors, nurses, social workers. They are there to answer your questions.
3. Develop a list of people and organizations that you want to contact.
4. If someone from the media wants to write a story about you, be prepared and provide them with some written material about your condition. Reach out to local newspapers or schools and churches that have newsletters. They might be interested in writing "your story."
5. Online groups, Facebook etc. are outlets where your story could appear.
6. Know what you'll say when you meet people. You are always given the opportunity to let others know about your need....every day you are asked, "how are you," or "what's new." If you are prepared, you'll be able to tell "your story."
7. Many people "get lucky" when they let others know about their condition. **"Luck Happens when Preparation Opportunity."**

### Telling "Your Story" don't "Ask" someone to donate:

1. The first few people you speak to will probably be the hardest as you struggle with the words. Speak from your heart. Find a person who will listen with support and encouragement, then role play with that person until you feel comfortable conveying your message.
2. Start talking to family members and friends. Get comfortable telling your story.

## Reaching Out

1. Most people say that it gets easier each time you speak to someone else. Be open and honest. Speak from your heart. The more people you speak to not only increases the likelihood that someone will offer to learn more about your situation, but will also increase the number of people that you could lean on for support.
2. It is important when talking to family members, that you do not pressure anyone to donate. The decision to donate is a personal one, any outside pressure is inappropriate and may cause long lasting personal and family problems. Also, you should make it clear to anyone who shows an interest in donating that they can change their mind at any time and you will respect and accept that decision.
3. Local radio and television stations may be interested in doing a story about you. Many media companies have a "Health Editor" who may already know, (from reading other stories,) about the challenges facing people who need a kidney transplant. A local story will not only reinforce to the people who already know about your situation, but could also reach other people who you know, but are still unaware of your condition.
4. To help media outlets show an interest in you, prepare something in writing that you could send to them.
5. Schools, churches, community centers, not-for-profit and many other organizations have newsletters. They may be interested in writing a story about you.
6. Reach out to your place of worship and to other organizations. The clergyman can inform the congregation of your need. You may want to post information on their bulletin board.
7. Using the internet and email isn't for everyone. Understand the risks and rewards from using these mediums.

## When Someone Offers to Donate, What's the Next Step?

The first thing you'll want to do is thank that person. You will want to express to them that at any time and for any reason if they feel that they do not want to continue with the process that they will always have that option. There's a chance that someone that offers to donate may not be medically suitable to be a donor. If someone is not suitable, they could still help you by advocating on your behalf. You could provide them with the name of the donor transplant coordinator at your hospital to discuss the evaluation process.

Just because one person offers to be a donor doesn't mean you stop the process of reaching out. You want to have backups in case that person doesn't work out. It might take a month or more for someone to be evaluated. Don't lose that time should they not be a suitable donor, healthy enough to donate. Also, ask your hospital about their evaluation process. There isn't a national standard for evaluating donors. Each hospital has their own policy.

## What To Do First

The old saying, "every journey starts with the first step" has meaning for you and your journey. Your first step should be a small one. Don't try to accomplish too much. Take small steps, or even just one step. Choose one new idea and try it out. Gain some confidence and momentum with a few small successes, then move on to another. Share your successes and challenges with others. Support them, and they'll support you too.