

# FIND YOUR SUPPORT PERSON

You can't do this alone, but you probably have more help than you think.

## What is a Transplant Support Person?

Immediately after your kidney transplant, you will need help on-hand 24/7. Your support person (or people) will stay with you, bring you to appointments, prepare your meals, and help you safely navigate daily activities. Your support person is on-call from the time of your evaluation, through your surgery, and for an additional 8-12 weeks after transplant. **You will not be approved as a transplant candidate without a support person.**

## Choosing a Support Person

Your support person might be a spouse, parent, adult-child, friend, or relative. They may do everything themselves or lead a support team to work in shifts or take on specific tasks. This might include setting up a meal train, assigning runners for the pharmacy or other errands, going with you to follow-up appointments, or taking care of a pet.

Think creatively about who might be able to help! Your friend who is always in the kitchen might enjoy meal prep. Your neighbor who works near the pharmacy would probably pick up your prescriptions. Faith communities, neighborhood groups, service organizations, and alumni associations can all come together to fill these roles. You probably have more support around you than you think.

Some people in your life may not qualify as your transplant support person. Your living donor will not qualify as they will also be recovering from surgery. Paid caregivers are not generally included.

## Tips for Success

- **More the merrier!** – Most people who hear your journey will want to help, but they don't always know how. Inviting them to be part of your support team can be a great option to lighten your load in a way that fits their life.
- **Explore FMLA** – Your primary support person might qualify for time off from work under the Family Medical Leave Act (FMLA). Ask your social worker for help exploring that option.
- **Have a Contact Plan** – Make sure everyone on your support team has a way to contact one another and knows the communication plan if you are called to receive your transplant. A shared digital calendar, private social media page, or group messaging platform can be set up in advance and help keep everyone organized when your surgery date arrives.
- **Talk About Changes** – The wait for a kidney can take years. Life circumstances for you and your primary support person are likely to change. Tell your transplant center as plans change.
- **Remember to Show Thanks** – Nobody is at their best when recovering from major surgery or taking care of a loved one. Look for opportunities to show appreciation. Simple gestures like saying “please” and “thank you” or offering a warm greeting make a big difference.

• National Kidney Foundation		Local Programs and Events
<b>Patient Support Line</b> 855.NKF.CARES (855.653.2273)	<b>Transplant Resources</b> <a href="http://www.kidney.org/transplantation">www.kidney.org/transplantation</a>	<b>National Kidney Foundation of WI</b> 414.897.8669 or <a href="mailto:info@kidneywi.org">info@kidneywi.org</a>

# TRANSPLANT SUPPORT ROLE

A Starter Guide of What to Expect as a Primary Support Person

## What to Expect as a Support Person

### Before Transplant

- **Go to Appointments** – Provide transportation, be an extra set of ears, and ask questions to be sure you and the transplant candidate understand what is being said.
- **Get Informed** – Familiarize yourself with reliable resources like National Kidney Foundation and the transplant center’s website. This will help you be a better resource in navigating the process.
- **Understand Patient Goals** – Have honest conversations with the candidate about their priorities and keep those goals in mind when talking to their doctors or other people on the support team.
- **Be in Touch** – No matter the size of the support team, have a plan for sharing updates with everyone. Help the candidate to report any changes in medicine, health, or insurance.
- **Recognize Your Limits** – This role can be physically and emotionally demanding! Plan for your own self-care and be honest about any changes in your ability to provide support.
- **Write a Plan** – Work with the transplant candidate to make checklists for paying bills, household tasks, kidney-friendly recipes, pets or childcare, and any other details you can plan for.
- **Be Ready** – Pack a “go-bag” with anything you might need for when your loved one gets the call.

### After Transplant

- **Be Flexible** – This is a major surgery. Understand that you may need to provide 24/7 support post-transplant due to delayed graft function (if the kidney does not “wake up” right away).
- **Provide Transportation** – Plan to get the recipient everywhere they need to be for at least 4 weeks. This includes continuing to join doctor’s appointments and frequent pick-ups from the pharmacy.
- **Implement the Plan** – Break out those checklists of kidney-friendly recipes, bills to be paid, and pet or childcare needs. If there are others on the support team, make sure everyone is in touch with each other and knows their roles.
- **Be a Good Listener** – This can be an overwhelming time for the patient. Listen and support them as they process the fear, anxiety, and joy of this life-changing surgery.
- **Provide Reminders** – Following the care plan is the most reliable path to a strong recovery. Reminders about walking, taking medicines, or dressing changes may be necessary.
- **Be Mindful of Your Limits** – Remember your self-care plan and be honest about how much support you can provide.

## Expectations for Patient

- **Give Yourself Grace** – It is okay to ask for help. Remember that this is temporary and focus on what life after transplant could look like for you.
- **Be Honest and Direct** – Talk to your support person about what is most important to you, your boundaries, and any uncomfortable details they might need to be aware of (financial or medical).