

# BEING A TRANSPLANT CAREGIVER

When your loved one needs a transplant, the lives, roles, and responsibilities of the whole family often change. Remember, the transplant process is more like a marathon than a sprint. As you go through the transplant treatment process with your loved one, it's important that you take care of yourself so you can stay healthy.

## READ ON TO **LEARN ABOUT:**

- Who can be a caregiver
- What a caregiver does before and after transplant
- How to take care of yourself while you're a caregiver
- Resources to help you be a caregiver

## WHO IS A **CAREGIVER?**

A caregiver is someone who will be there to support and care for a loved one throughout the transplant process. As a caregiver, you play an important role in the patient's treatment and recovery. In fact, most transplant centers require patients to have a caregiver before transplant.

### **A caregiver can be:**

- A spouse or partner
- Adult children
- Brothers or sisters
- Parents
- Friends or co-workers

As a caregiver, you may be asked to help with medical, financial, and emotional needs. The job of being a caregiver can seem overwhelming. It helps if you know what you will need to do. The doctors, nurses, and social workers at the transplant center will help you learn about your role. Be The Match® also supports caregivers with programs and resources.

## WHAT DOES A CAREGIVER DO **BEFORE TRANSPLANT?**

When someone you love enters the hospital for a transplant, you may be there with them all day, most days of the week, and in some cases all night, too. Even before transplant, your loved one might need some extra help and support.

### **To support your loved one in his or her medical care, you can:**

- Be with your loved one in the hospital or clinic during doctor visits to listen and ask questions
- Ask the doctors to explain treatment choices, test results, and medicines
- Keep track of all the treatments in a notebook
- Talk with your loved one to understand treatment goals

### **To provide support with finances, you can:**

- Find out what insurance will pay and what you or your loved one will need to pay
- Ask the social worker or financial coordinator about other financial help
- Help plan how to pay for out-of-pocket transplant expenses
- Help keep his or her health insurance and other benefits active



### **To provide emotional support, you can:**

- Be there to listen, to talk, or to simply be by your loved one's side
- Understand his or her concerns and help make a plan to take care of concerns
- Spend time doing things you both like to do
- Help communicate with your loved one's family and friends

### **WHAT DOES A CAREGIVER DO AFTER TRANSPLANT?**

The day the patient comes home after a transplant is usually a happy one. Everyone is glad to be coming home. However, it can also be frightening to leave the constant care of the transplant team in the hospital. Your loved one may need a lot of help from you. Many caregivers find they have more to do now than during the hospital stay. You may feel ready for your lives to be more normal, but recovery can take a long time.

### **Before leaving the hospital, the health care team will teach you:**

- How to care for your loved one at home
- What to do if there is an emergency
- Who to contact with questions

Once you get home from the hospital, one of your most important tasks is to watch for new symptoms or problems and report them to the doctor right away. That's because waiting to report symptoms could cause serious complications.

### **You may also need to:**

- Help your loved one take the right medicines at the right times
- Care for the central line, if it's still in place
- Take him or her to appointments at the hospital or clinic — sometimes on short notice
- Protect your loved one from infections by cleaning the house and caring for children and pets
- Cook food safely and help him or her follow any rules about what is safe for to eat

Remember, you may need to be available all of the time, in case your loved one needs medical help right away.

### **CAN THERE BE MORE THAN ONE CAREGIVER?**

Most often, one person is the main caregiver. Sometimes a group of people can work together as caregivers. Even if you are the main caregiver, you should try to find tasks to give to others.

When a group shares the caregiving role, organization and communication are keys to success. You can:

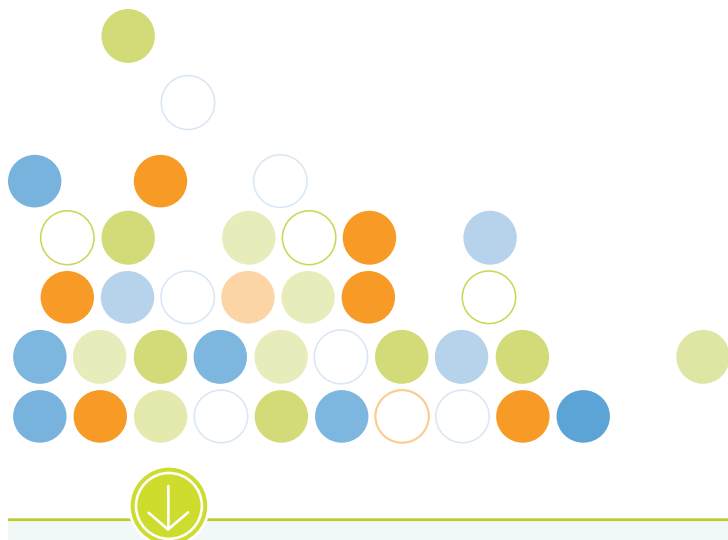
- Organize a community of family and friends to help. A free online tool, called Lotsa Helping Hands, is available at [lotsahelpinghands.com](http://lotsahelpinghands.com). With this private group web calendar, people can see what help is needed and when, so everyone can pitch in to help make your life run more smoothly.
- Organize a caregiving team. For ideas, visit [ShareTheCare.org](http://ShareTheCare.org).

### **IS THERE SUPPORT AVAILABLE FOR CAREGIVERS?**

As you focus on caring for your loved one, it can be easy to forget about your own needs. But one of the most important things you can do is take care of yourself, which will help you take better care of your loved one.

### **Here are some suggestions for you:**

- Take time out for yourself every day, even if it is only 15 minutes. Talk to your friends or spend a quiet moment away from your loved one to do something that helps you feel rested.
- Find someone to talk to who can give you emotional support. If the person you usually count on is the transplant patient, they probably can't fill that role right now. You may be able to find support from friends or family members, other caregivers, or support groups.
- Focus on what's important. You can't do everything. Reserve your energy for what really matters to you and your loved one.
- Ask for help. Be willing to give some of your daily and weekly tasks to friends and family members who want to help.
- Do something you love. Pick something that reminds you of the parts of your life that may be put on hold while you are focused on caregiving.
- Give yourself credit for the work you are doing. Sometimes people focus on the patient and forget about everything you are doing.



## FREE RESOURCES FOR CAREGIVERS

Be The Match offers many free resources to help you take care of your health, so you can be a more effective advocate for your loved one.

To learn more about any of the programs listed below call **1 (888) 999-6743** or email **patientinfo@nmdp.org**.

- Patient services coordinators provide one-on-one professional guidance and education by answering questions, sharing resources, and providing support.
- Peer Connect Program puts caregivers in touch with other caregivers to provide support and guidance to one another over the phone or through email.
- Caregiver's Companion Program and Parent's Companion Program combine a useful toolkit with the personalized, confidential telephone support of a coach, to help you manage emotional and physical stress. The programs are for caregivers who are caring for a transplant patient and parents who are caring for a child during or after transplant.

## AT EVERY STEP, WE'RE **HERE TO HELP**

**As you journey through transplant, you're not alone. Be The Match® is ready to help.**

We offer many free programs and resources to support you, your caregivers and family members before, during and after transplant. Connect with us in the way that works best for you.

LEARN: **BeTheMatch.org/patient**      EMAIL: **patientinfo@nmdp.org**

ORDER: **BeTheMatch.org/request**      CALL: **1 (888) 999-6743**

Our programs and resources offer support in 11 languages, including Spanish bilingual staff, and translation is available in more than 100 languages.

VISIT: **BeTheMatch.org/translations**



Every individual's medical situation, transplant experience and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.