

Being a Transplant Caregiver

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

This fact sheet tells you:

- Who can be a caregiver
- What a caregiver does
- How to take care of yourself
- Resources to help you

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 identified before transplant.

A caregiver can be:

- A spouse or partner
- Adult children
- Siblings
- Parents
- Friends or co-workers

Sometimes a group of people work together as caregivers. Even if you are the main caregiver, try to find tasks to share with others.

When a group shares the caregiving role, it's important to talk with each other to stay organized. These free tools can help:

- LotsaHelpingHands.com – Offers a private online calendar, so caregivers can see what help is needed and when.
- ShareTheCare.org – Offers resources and support for caregivers.

What does a caregiver do before transplant?

Even before transplant, your loved one might need some extra help and support. Here are some things you can do to help:

Medical care:

- Be with them 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 or electronic device.
- Talk with your loved one to understand treatment goals.

Finances:

- 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 health insurance and other benefits active.

Emotional support:

- Be there to listen, talk, or to simply be by your loved one's side.
- Ask about their concerns and help make a plan to cope with or resolve them.
- Spend time doing things you both like to do.
- Help communicate with your loved one's family and friends.

“AS YOU GO INTO THIS AND YOU KNOW YOU’RE GOING TO BE THE PRIMARY CAREGIVER, YOU PROBABLY NEED TO GET YOU A CAREGIVER TOO.”

— Steve, caregiver for his wife, Patsy

What does a caregiver do after transplant?

The day the patient leaves the hospital can bring mixed emotions. Sometimes caregivers feel relieved to reach this milestone in recovery. And, sometimes caregivers feel worried to leave the care provided in the hospital.

Keep in mind, recovery takes time. You may have more to do now and you may need more help.

Before leaving the hospital, be sure to ask the health care team:

- 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, watch for new symptoms and tell your doctor right away.

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 them to appointments at the hospital or clinic – sometimes on short notice
- Protect them from infections by cleaning the house and caring for children and pets
- Cook food safely and help them follow any rules about what is safe to eat

Remember, you may need to be available 24 hours a day 7 days a week, in case your loved one needs medical help right away.

Take time for yourself

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. Here are some tips:

- Take time out for yourself every day. Even if it's only for 15 minutes, do something that helps you feel rested.
- Talk to someone you trust. If the person you usually count on for emotional support is the transplant patient, they probably can't support you now. Look to support from friends or family members, other caregivers, or support groups.

- 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.
- Be kind to yourself. Remember, you are managing a lot.

Resources for you

Talk to someone who can help:

- Contact a BMT Patient Navigator:
 - Call: 1 (888) 999-6743
 - Email: patientinfo@nmdp.org

Talk to someone who understands:

- Connect with other caregivers:
 - Visit: nmdp.org/peerconnect
 - Visit: nmdp.org/supportgroups



At every step, we're here to help

NMDPSM has a team dedicated to providing information and support to you before, during, and after transplant. You can contact our Patient Support Center to ask questions you may have about transplant, request professional or peer support, or receive free patient education materials.

Call: 1 (888) 999-6743

Email: patientinfo@nmdp.org

Web: nmdp.org/one-on-one



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.