Role of the Family Caregiver

Your transplant center will ask you to identify a caregiver who can be your advocate and care for you when you return home.

A bone marrow or stem cell transplant is not a procedure you can manage by yourself.

Your transplant team will ask you to identify a full-time family caregiver who will be available to help you during transplant and your recovery period.

Most transplant centers will not allow a patient to go forward with a transplant unless a dedicated caregiver has been identified.

Typically, a close family member serves as the caregiver. Patients without close family members may need to reach out to extended family members or friends for help, or hire a temporary caregiver. Some patients assemble a team of caregivers.

Why You Need a Full-Time Family Caregiver

While you undergo treatment, you will be too ill and weak to manage your medical and household affairs on your own for several weeks or months. A full-time family caregiver is needed to ensure that you promptly get the medical attention you need, and that your household is a safe environment.

While you are in the hospital, your caregiver will be responsible for:

- telling the medical team about any changes in your condition
- providing you with emotional support
- advocating for your needs and helping with decision-making
- communicating with family and friends

After you're discharged from the hospital, your caregiver will assume additional duties including:

- transporting you to the outpatient clinic daily or weekly
- keeping track of your medical appointments
- making sure you take your many medications according to schedule
- taking care of dressings and your central venous catheter
- reporting changes in your condition to the medical team
- monitoring you for signs of infection and other complications
- encouraging you to eat
- in some cases, providing you with intravenous medications

In addition, your caregiver will need to ensure your home environment is safe. This includes:

- cleaning and cooking according to the guidelines provided by your transplant team
- protecting you from sources of infection, such as visitors with colds or those who have been around sick people
- helping you move safely, if you need help

Being a Caregiver is a Stressful Job

Caring for a transplant patient is physically challenging and emotionally draining. Watching as a loved one undergoes a difficult medical procedure taxes even the most optimistic caregiver. Helping other family members cope with the experience adds to the burden.

People who have been a caregiver for a recovering transplant patient agree on one thing: You must take time to care for yourself, in order to be an effective caregiver.

As a caregiver, there are several things you can do to help you maintain a balance while caring for your loved one.
• Set up a separate support system for yourself.

Special friends, a spiritual advisor or a mental health counselor can be good sources of support during the difficult transplant process.

• Keep a diary and carry it with you.

Write down everything. So much is said and done during the transplant and recovery period that remembering it can be hard. If writing it all down is difficult, consider recording notes on a cell phone or tablet. You can also use a diary just for you, as a place to write down your thoughts and feelings.

• Take time to recharge yourself.

Try to eat well-balanced meals, get some exercise and get enough sleep. Carve out some alone time to get your thoughts off the job at hand. It's OK to read a book, watch a movie or go for a walk. It's good to take mini-breaks throughout the day.

• Try some relaxation techniques.

Information about using relaxation techniques can be found on the Mayo Clinic website[1] and the National Institutes of Health website[2]. A guided meditation video[3] by Deepak Chopra may help you get started.

• Learn to accept help.

This is one of the most common mistakes: caregivers think they can do it all by themselves. Don't fall into that trap. Friends and family want to help. Provide them with concrete suggestions on how they can help so you can get some relief. It will make them feel useful as well.

• Set up a system to update people about the patient's progress.

Everyone who knows you and the patient will want to know how things are going. Consider creating a free personal web site at CaringBridge[4] or use Facebook to keep friends and family informed. Twitter is a good way to send out quick updates. You can also record a new message on voice mail or your answering machine every few days to let people know how things are going. Having a friend take charge of communicating with well-wishers can relieve you of this task.

• Be an advocate for the patient.

Ask questions and get answers. Be politely assertive and make sure the patient's needs are being met.

• Be flexible and patient.

Focus on things you can control and try to let go of things you can't. The treatment and recovery period will be full of ups and downs. Try to have realistic expectations about how quickly your loved one will recover, and take things a day at a time.

Coping Strategies for Caregivers

The road to recovery may be smooth, or there may be setbacks and delays along the way. There are several skills that can help you successfully manage your caregiver role.

The first is flexibility. Be prepared for changes in medications, appointment schedules and the patient's status or mood. The recovery period may be much different than you expected. Be prepared to adapt.

Set realistic goals for yourself and the patient. You may not be able to accomplish everything you would like to do in a day. "Good enough" may be a more realistic and achievable goal than perfection.

Tap into your problem solving skills. Think of creative strategies for managing unexpected situations and reach out to family and friends for help.

Develop a Plan to Manage Stress

• Find a friend, a counselor or other caregivers with whom you can share your feelings and get support.

• BMT InfoNet's Caring Connections Program[5] can put in touch with another caregiver who understands your concerns.

• Find a caregiver support group at your transplant center, a local hospital or at a cancer wellness center.

• Websites like Facebook[6] and SmartPatients[7] have discussion groups for transplant survivors and caregivers.
Some caregivers find that setting aside time for meditation, writing in a journal, working on a hobby, practicing yoga or simply doing something that is fun helps to relieve stress. If you would like to explore meditation for relieving stress you can try Meditation Studio [8] - an app for mobile devices - or a relaxation video [3] by Deepak Chopra.

Watch a Video about What's Involved in Being a Caregiver for a Transplant Patient

Watch a Video about Caregiver Challenges and the Importance of Self-Care

(To view this page in Spanish click here [9])

Next Page: The Transplant and Early Recovery Period [10]

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