

“It helped us to simplify our life. This way the only thing on our minds was the transplant.”

— BMT Survivor

CHAPTER 3



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Important Things to Think About

Caregivers

Role of the Caregiver

The caregiver is someone who helps to care for you during and after your transplant. This person plays a very important role in the success of your transplant. In fact, a caregiver plays such an important role that you **must** have a caregiver in order to have a transplant at City of Hope.

The caregiver generally supports a patient throughout the transplant process. He or she may be called on to stay with the patient for long hours, talk to doctors, nurses and other members of the health care team, and support the patient in many other ways. The caregiver, along with the patient, is an active member of the health care team.

Most patients have one particular person who acts as the main caregiver. However, it is often not possible for one person to fill the role full time. Instead, several people can share the role of caregiver. If this is the case, it is important for all caregivers to communicate and organize their efforts.

The patient's needs change over the course of the transplant process, from pretransplant preparation, hospital stay and through the recovery process. It is important for the caregiver to know what to expect. Therefore, the caregiver needs to know as much about the transplant process as possible.

Caregiver Responsibilities

The caregiver must:

- Be at least 18 years of age and physically able to fulfill the caregiver role (*see below*).
- Provide transportation to and from City of Hope for both pre and post transplant appointments. Post transplant, autologous patients usually are required to see the doctor once or twice a week until the doctor is comfortable with decreasing the frequency. Allogeneic and unrelated transplant patients are required to see their doctor twice a week during the first 100 days, post transplant, or as need arises.
- Be able to reach the patient within 30 minutes at all times and be physically present 24 hours with the patient if residing within Hope/Parsons Village.
- Assist the patient with their activities of daily living depending on the patient's physical abilities, such as lifting, helping the patient to move from the bed to the toilet, walking, bathing, assisting with dressing, meal preparation, Hickman care and

making sure the patient is taking their medication properly. Some patients may need more assistance than others.

- Observe changes in patient's condition and report them to the doctor, if indicated.
- Serve as a communication link if needed between patient and medical staff.
- Give encouragement to the patient while taking time to care for yourself.

Choosing a Caregiver

Your caregiver is an important part of your care and will be an important part of your life throughout the transplant and recovery period. For many people, their natural choice for a caregiver is a spouse, partner, parent or other close family member or friend. Some may even have several people share the caregiver role. In any case, it is important for you to think very carefully about who you will ask to take on this responsibility.

The following questions are taken from the National Marrow Donor Program website at www.marrow.org and may help you to think of questions to ask yourself when deciding on a caregiver:

- You might have to be at the hospital for long periods of time. Is this person comfortable in the hospital setting?
- Will your caregiver be able to take you to your medical appointments?
- Can she or he deal with stressful situations?
- Your caregiver may have to be away from his or her work for weeks or even months. Is your caregiver able to take a leave (such as Family Medical Leave Act – FMLA) or an extended absence from work? Does he or she have a good means of support that will allow for unpaid time off?
- Are you and your caregiver able to get along most of the time? Do you get over disagreements easily?
- Will your caregiver support your health care choices?
- Will your caregiver be a strong advocate for you?

Questions and Tips for Caregivers

A transplant is difficult, not only for the patient, but also for family members and caregivers. This is especially true if the support person has ongoing family and/or job responsibilities. Here are a few questions and tips that may help:

- Ask what you will do as a caregiver.
- Ask what you need to know as a caregiver.
- Ask how long you will be a caregiver.

- Ask yourself how you will manage being away from work for extended periods and how you will take care of your own responsibilities while you are a caregiver.
- Don't hesitate to ask other family members and friends for help in caring for the patient, your family and you during the transplant. You will need help and others concerned about the patient's well-being will appreciate the opportunity to lend a hand.
- Be realistic about your limitations. Get enough sleep, eat properly and take time off for yourself. You will be a bigger help to the patient if you are healthy and calm, rather than sick and overwhelmed.
- Be prepared for changes in the patient's behavior. The drugs and stress may cause the patient to become depressed or angry. He or she may say things that don't make sense or see things that aren't there — these changes are only temporary but can be frightening when they occur.
- At the same time, understand that your loved one needs you now more than ever before. Your help is not only welcome — it is absolutely essential.
- Don't be shy about tracking down the medical staff to get help or answers to your questions. You'll feel better knowing the doctors and nurses are aware of problems you've noted. You are entitled to have all of your questions answered fully.
- Remember that as helpless as you may sometimes feel the moral support you provide is often the best "medicine" the patient can receive.
- City of Hope clinical social workers are available to talk to family members and caregivers to assist you and provide support and resources to help you through this time. If you would like to talk to a social worker, call the Clinical Social Work office at ext. 62282.

For More Information:

The following booklets may be helpful for you.

- *A Caregiver's Guide: Tips and tools for reducing caregiver stress.* (City of Hope)
- *Caregivers' Guide for Bone Marrow/Stem Cell Transplant* (nbmtLINK)
- *Caring for the Caregiver* (National Cancer Institute)
- *When Someone You Love is Being Treated for Cancer* (National Cancer Institute)

These booklets and more are available in the Sheri & Les Biller Patient and Family Resource Center.

Finances

You will be asked to provide your insurance and financial information when accepted as a patient. Medicare and all types of insurance are accepted.

We have contracts with many health maintenance organizations (HMOs), preferred provider organizations (PPOs) and employer insurance groups. (Please note: Medical authorization is required on most of these contracts before treatment.)

Whether you are an inpatient or outpatient, please remember to carry your health insurance identification card at all times. This will make things easier for you and for various departments that might need this information.

Financial Support Services

Financial Support Services (FSS) assists with outpatient registration, securing insurance authorizations, referral/benefits/eligibility and insurance verification, financial counseling, charity care screening, medical necessity screening, assignment of patient account and medical record numbers, and up front cash collections.

FSS interacts with patients, families, visitors and doctors regarding outpatient registration activities and ensures an efficient and effective process for patient intake. The staff serves as a problem-solving resource for insurance and financial issues in support of City of Hope's mission to provide caring and compassionate service to our patients, and superior customer service to our clinicians and colleagues.

Financial Counselors

By the first letter of your last name:

(A - D)

(E - I)

(J - N)

(O - R)

(S - Z)

Services provided by this facility are available to all persons living or working in this area. This facility is prohibited by law from discriminating against any person, including Medi-Cal and Medicare patients. If you believe you may be eligible for Medi-Cal or Medicare and are in need of a doctor to provide you with services at this facility, please contact our business office. Refusal of services at this facility is in violation of the community services requirement. Should this occur, please contact Julie Weber, manager, Financial Services/Patient Access at City of Hope (626) 256-4673, ext. 68342, and the California Health Facilities Financing Authority at (916) 653-2995.

Advance Directive

What is an AD?

An advance directive (AD) is a verbal or written instruction that tells your family and health care team what you want done in case you have a serious injury or illness and are not able to speak for yourself. If you already have an AD, you may bring a copy of it and we will place it in your medical record.

What are the benefits of an AD?

Having an AD will help your family have a clear statement of your wishes for health care in the event you are not able to speak for yourself. You will feel confident that your medical decisions will be respected.

How do I complete an AD form?

It is important to discuss your advance directive with your family ahead of time. For more information read through the City of Hope booklet *Making an Advance Directive* available in the Sheri & Les Biller Patient and Family Resource Center. If you have further questions about completing your AD, please speak with your doctor, clinical social worker or both.

City of Hope can provide you with an advance directive form or you may use your own. This is a legal document and will need to be witnessed or notarized. You may speak with a lawyer if you think it would be helpful, however it is not necessary. City of Hope has notary services available.

Other Responsibilities

You will also need to make arrangements ahead of time to manage your other responsibilities during your hospital stay and recovery period. Bills need to be paid and your home needs to be maintained while you are in the hospital. You may need help with these things during your recovery period as well. Think about the people who can do these things for you and talk to them well in advance. Make sure they understand exactly how they can help you.

Family and Friends

Your transplant will have an impact on your family and friends. You may be away from them for extended periods and they may become worried or anxious. You can help your family and friends by telling them what to expect during and after your transplant. Let them know that your needs will change throughout the process and how they can best help you during this time.

Families with Children

If you have children it is best to be honest with them and let them know what is going on. A City of Hope child life specialist is available to help your children adjust to the changes brought about by your treatment and recovery period. If you would like to know more about child life services, please ask your doctor for a referral.

Family Spokesperson

Communication with family and friends is important. It may be helpful to designate someone as a “family spokesperson.” This is someone who can be the main contact person between your friends and extended family and you. The family spokesperson can relay information and questions and will help to avoid confusion and misinformation.