

NIH Clinical Center Patient Education Materials

Emotional aspects of blood and marrow transplantation: What you may feel and how we can help

Emotional experience

We all have different ways of coping with the stress in our lives. The stress of the transplantation process (before, during, and after the transplantation) will also vary for each person. Despite these differences, many people undergoing blood or marrow transplantation will share similar feelings and worries. Going through a transplant can be physically, emotionally, and psychologically difficult for both the patient and his or her family. It is important to know that your healthcare team is available to assist you and your family members through every step of the transplant.

The decision to pursue transplant

Being diagnosed with a disease that requires transplant can be a stressful and traumatizing event. Having a transplant carries not only a sense of excitement and hope but also a sense of worry and fear for what may happen. Frequent changes in how you feel are common. For example, one day you may feel tired, but happy. Other days, you may feel irritable and sad. It is also common to feel all of these emotions at once.

What to do?

It is important to let a member of your healthcare team know how you feel so that the team can understand your concerns and worries and help you. The more team members know, the more NIH Clinical Center services they can make available to you, including social work, spiritual ministry, psychiatry consult liaison, pain and palliative care, massage therapy, and community outpatient services.

The transplant

The medications that are given before transplant can make some people feel sick. Some people have nausea, vomiting, fever, diarrhea, and fatigue. These symptoms can be stressful to both the person experiencing them as well as his or her caregivers. Not feeling well can limit how much you can do, and this is where caregivers can help.

What to do?

Some patients who have a transplant may think that they “should” be able to handle all of their physical or emotional symptoms. While you may be able to handle some symptoms, it is important not to dismiss them when they become hard to manage. Please let your healthcare team know which symptoms are hard to cope with and how you are managing emotionally. Often, making changes in your medications or treatments can help you feel better.

Isolation precautions

During your transplant, you may have an infection that requires special isolation precautions. These precautions may require limiting your activity to your room as well as having visitors wear masks, gowns, and gloves.

What to do?

Many people find it helpful to keep busy with a variety of activities.

- You will have a television in your room, which is also a computer and DVD player. You can e-mail and video conference with your friends and family on this computer.

- Recreation therapy staff can bring crafts and games.
- You can choose a book or movie to enjoy in your room from the Patient Library.
- Be sure to let your healthcare team members know if you feel isolated, because they can help put the right supports in place.

Guarding your privacy

Because many people on your healthcare team need to know personal details about your day-to-day progress during the transplant, maintaining your sense of privacy in the hospital may be difficult for you. You may also feel helpless when you need to rely more on others to help you with daily activities during the transplant process.

What to do?

Let the staff know if and when you need time to yourself, or when you prefer to be awakened for things such as vital signs. If there are times when you do not want visitors (except staff that need to provide medical care), the nursing team can make sure that appropriate signs are placed on your door so that your wishes are respected.

Leaving the hospital

Emotional ups and downs can continue even after leaving the hospital. Those who have gone through a blood or marrow transplant often describe having some days when they feel better and other days when they feel poorly. Some people find it harder to cope after leaving the security of the hospital.

What to do?

Feelings of being up and down, frustrated, and a little sad are normal reactions after a long, intense hospital stay. It is very important that you share these feelings with your healthcare team so that we can provide the best support to you.

For family and friends

Each family adapts to the transplant process differently. Some families share care responsibilities easily while others express anger or blame. Others may feel guilt for not being able to contribute as much or feel that they want to do more.

What to do?

It often helps for families and friends to choose responsibilities ahead of time, so that decisions are not made under stress. When possible, rotate responsibilities to allow all members to feel equally involved. It also helps to have family meetings with the healthcare team when important transitions in treatment occur. This allows everyone to be equally informed and ask questions.

Specific issues for children and adolescents undergoing transplant

When the patient having the transplant is a child or adolescent, a parent or caregiver will need to stay in the hospital with them at all times, including overnight. Some parents find this stressful as well as physically and emotionally exhausting. We recommend that parents/caregivers take turns.

The transplant experience is different for every child and depends on his or her personality, specific medical course, and physical symptoms. Often, being separated from friends and family is difficult. Siblings who stay at home can feel left out and helpless in the process, feeling as though parents and friends now focus all of their attention to the sibling undergoing the transplant.

During these times, the child or adolescent patient may direct anger and frustration at parents or siblings, while at the same time feel guilty for these thoughts or behaviors.

What to do?

- It is important for parents/caregivers to try and get rest and maintain healthy eating and sleeping patterns. For those who like to exercise, there are places in the hospital or at the Children's Inn where parents can exercise. The staff can help you to plan for some time away from the hospital during the day.
- It may help to bring objects of comfort and distraction from home to ease separation, isolation, and boredom. For example, bring games, a favorite toy/pillow, and e-mail addresses to maintain contact with peers.
- The NIH CC has a school, and the teachers work hard to coordinate each child's academic requirements with the home teachers or grade level. The school will contact you about your child's schooling needs.
- For the children at home, it is crucial to keep as much routine or "normalcy" in their lives as possible to reduce anxiety. Arrange a time each day to call home so that you can help maintain consistency in their lives. When possible, caregivers should rotate responsibility between the patient and other children so that they can stay involved in each child's life. Talk to your social worker about sibling programs and other tips to help family members at home.

Coping Strategies

- Talk to your health care team about your feelings and needs:
 - Your health care team has specialists to provide support and help you through this transplant process.
 - Let the team know how you like to learn about medical information and how much information you want to receive.
 - Open communication also helps address changes in your health and symptoms and helps you to adjust to the medication regimen.
- Accept support from family, friends, and community:
Families may hesitate to accept help from others so as not to be a burden. Families also may feel that they should manage it all on their own. The transplant process can be exhausting, and it helps to use whatever support that you can to conserve your energy and resources.

This information is prepared specifically for persons taking part in clinical research at the National Institutes of Health Clinical Center and may not apply to patients elsewhere. If you have questions about the information presented here, talk to a member of your health care team. Products/resources named serve as examples and do not imply endorsement by NIH. The fact that a certain product/resource is not named does not imply that such product/resource is unsatisfactory.

National Institutes of Health Clinical Center
Bethesda, MD 20892

[Questions about the Clinical Center?](#)

04/2015

