

EMOTIONAL RECOVERY AFTER LUNG TRANSPLANT

Social and Emotional Adjustment After Transplantation

Having a lung transplant may cause fear, anxiety, and stress. After surgery, you may feel overwhelmed, depressed, or worried about complications. All of these feelings are normal for someone going through a major surgery. It's important to talk about how you feel with your social worker, health care providers, and even other patients. Support from family and friends can also help relieve stress and anxiety. The first year of life after transplant is usually the most challenging. We encourage all patients and caregivers, whether you are pre-transplant or post, to attend the Lung Transplant Support Group held here at Michigan Medicine. Please refer to the Resources section for details.

A patient waiting for a lung transplant knows that when an organ becomes available a person has died. There is an emotional struggle between maintaining hope for a transplant and fear, knowing that a stranger will die before that becomes possible. Lung transplant recipients often report feelings of guilt, having benefited from the death of another.



It is important for recipients to remember that family members of organ donors report feeling that being able to donate organs was the only positive thing to happen during a heartbreaking time. You may want to consider writing to your donor family. Letters should not include any identifying information and should be forwarded to your social worker or nurse coordinator. Your social worker or nurse coordinator will send your letter to Gift of Life. Gift of Life will send the letter to the donor family. For more information about writing to your donor family go to www.giftoflifemichigan.org.

Physical Appearance

Transplantation requires a person to cope with a variety of changes in body image, an important piece of self-esteem. These changes are usually related to medication side effects. These unwelcome changes include weight gain, re-distribution of weight toward the middle of your body and face, a large scar, and unwanted hair or hair loss. When your doctor clears you, lung rehabilitation is an excellent way to get exercise and maintain a healthy weight. In addition, getting involved in volunteer activities, hobbies, and family activities help to move your focus away from negative changes.

Prednisone

Prednisone is one of the primary drugs used to prevent organ rejection. Some of its side effects are restlessness, joy, moodiness, anxiety and depression or any sudden swings between these affects. These changes are usually from high doses of prednisone. However, it doesn't mean that they won't occur for individuals on lower doses as well.

In most cases, the emotional effects are reversible and dose dependent. This means that the side effects will lessen as the dose of prednisone is decreased. Remember, only your doctor can make a change to your prescription. If you have mood changes including depression, severe anxiety, irritability, mania, or suicidal thoughts, talk to your social worker or doctor. He/she can make recommendations for additional treatment that may help with the emotional side effects from this medication.

Steroid-induced physical changes: The prednisone you take may increase your appetite and you may notice a weight increase. Additionally, the Prednisone affects your normal fat distribution and you may notice some weight gain especially in the face and belly. The best way to manage your weight change is through proper diet and exercise.

Hair growth: Some of your anti-rejection medications cause male pattern hair growth (hair on the face or ears). Though usually not a problem for men, it can be very hard for women. However, there are waxes and other methods of removing unwanted hair. Your doctor, nurse coordinator and social worker are sources of encouragement and emotional support. They should be consulted before addressing issues related to weight loss or chemical hair removal. While the idea of beauty in our society may be exaggerated, feeling good about yourself can make your adjustment to transplantation easier.

Sun Exposure: Transplant recipients run added risk of developing skin and lip cancers, and this risk increases over time. Prednisone and other after transplant medications can make your skin more sensitive to the sun, so you will burn easier, faster, and to a greater degree than you did before the transplant. Lengthy and repeated exposure to the sun's ultraviolet radiation produces permanent and damaging skin changes. The darker your skin, the more natural protection you have against burning and skin damage. But, bear in mind that you can now "burn" because your medications make you more sensitive to the sun.

You will not need any special skin care unless you develop problems with acne or dry skin. You should take a bath or shower as often as necessary (daily or every other day) to keep your skin clean. It is important to be aware that any lasting skin problem will require evaluation by a dermatologist.

Depression and Anxiety

Patients and their family members often overlook the symptoms of depression, assuming that feeling depressed is normal for someone struggling with a serious illness and recovering from transplantation. Symptoms of depression such as fatigue, poor appetite and lack of motivation, impaired concentration, and insomnia are also common features of chronic medical conditions, adding to the difficulty of deciding whether they are due to depression or to the illness. During the postoperative course of lung transplantation, patients may have depressive symptoms that negatively affect their ability to cope with recovery, their commitment to rehabilitation and medications, and their overall quality of life. Depression does not only impact people with unmet expectations or complicated recovery, it is common with chronic illness and major surgeries. Confronting depression and looking for treatment is a very important part of recovery from transplant and maintaining health for years to come.

We encourage patients to reach out to their Transplant Social Worker to discuss possible treatment options for depression, anxiety or any other psychological symptoms that you might be experiencing. It is important not to suffer alone, as there are many treatment options available, including a referral to our Transplant Psychiatrist or Transplant Psychologist. We are also able to make a referral to a mental health provider in your geographic area if you prefer.

Some symptoms of depression include:

- Loss of interest in normal daily activities
- Lack of motivation
- Feeling sad or down
- Feeling hopeless
- Trouble focusing or concentrating
- Hard time making decisions
- Irritability
- Restlessness
- Being easily annoyed
- Feeling fatigued or weak
- Feeling worthless
- Loss of interest in sex
- Thoughts of suicide or suicidal behavior

Relationships and Support System

Having an organ transplant has a positive effect on most recipients' lives. However, in the absence of the pre-transplant illness, there are still many things that can stress relationships.

Thinking of yourself as a normal, healthy person is sometimes one of the most difficult adjustments to make. You may find yourself avoiding independence, feeling afraid, and wanting your family and friends to do things for you. We know that patients generally make better progress when they have families who show concern and interest in their well-being. In some cases, however, it is the family who fears letting go, encouraging dependence. Instead, we hope your family will serve as coaches to encourage you to learn about your body and its abilities again. Slowly but surely, you will recover and regain your independence, taking responsibility for your own care. Just remember, if you are feeling excited, scared or tired, your family probably is too. This adjustment period is normal. Support comes from many sources. Reach out to extended family, work colleagues, neighbors, community organizations, religious or spiritual groups, or supportive friends. A group may offer to provide meals, transportation, and/or assistance with light home chores while you are recovering from your transplant.



Communication with other lung transplant recipients and participation in support groups will further teach you about the post-transplant process as well as reduce any anxiety you may have. Support groups for adults and family members often help during stressful times by providing answers to commonly asked questions and mutual support from others who have been in similar circumstances. Participation in the lung transplant group is recommended after transplant. Talk to your lung transplant social worker to get an up to date schedule or ask about local support groups.

Online support can be found for information, connecting with transplant survivors or talking electronically with others. Remember that medical opinions shared by others or information received over the Internet does not substitute for advice given by your doctor or transplant team.

A Special Note for Caregivers

A caregiver is anyone who provides unpaid assistance to another adult who is ill, disabled or needs help. Studies show that in many American households, a person over the age of 18 provides care to someone over the age of 50. These individuals report stress and strain.

Now that the transplant has come, your caregiving role may not be over. However, that doesn't mean that your loved one's transplant should always take center stage. The major follow-up that transplant recipients require may add further to stress levels and can have serious physical and emotional consequences.

When you are taking care of others, it is important to love, honor and value yourself. Taking care of yourself and your needs is like performing regular maintenance on your car. It is critical to staying in shape over time. Below are some things you can do:

- Eat healthy
- Get enough sleep
- Get regular medical check-ups
- Exercise
- Address symptoms of depression (moodiness, loss of appetite, difficulty or too much sleeping, decreased mood)
- Maintain or establish social contacts
- Seek support from family or friends - they can help with household tasks
- Set priorities and realistic goals: make a list, arrange your day, pace yourself, and set limits.

Sexuality

Sexuality is an important part of who you are as a person. It is more than sexual intercourse. Sexuality involves how you feel about yourself as a man or woman, the giving and receiving of sensual (feeling) pleasure, the desire for closeness with another person, and the release of sexual tension.

A person's sexuality is affected when they have lung failure. This is caused for lots of reasons. Men may have impotence (problems getting or maintaining an erection) and a decreased sexual drive (libido). Women's menstrual cycles may become irregular or stop completely. Medications can also interfere with sexual function. They can cause drowsiness and fatigue, in addition to decreased sexual drive, menstrual cycle irregularities, and/or decreased vaginal lubrication. Sometimes, even though the body functions normally, sex is not enjoyable. Some patients have found talking to a counselor helpful, and this can be arranged by the transplant team.

Patients who successfully undergo a transplant are excited to return to a normal, active life. Yet immunosuppressant medications that help prevent rejection of a transplanted organ can have side effects, including impacts on patients' sexuality. Changes in body image or sexual desire post-transplant can disrupt old behavior patterns or lead to insecurities about starting new relationships. Often the physical toll of the transplant and the resulting side effects such as nausea and lower energy levels may reduce the desire for sexual activity. In other cases, worry or depression or nervousness about one's ability to "perform" and to be sexually attractive post-transplant may also result in loss of desire. This can happen in the form of impotence for men, but you should check with your doctor to rule out a medical cause.

Illness and sexuality: The presence of disease can greatly affect self-concept and sexual activity. After a transplant, when the disease is absent, one is sometimes left with feelings of anxiety, fear, depression and anger. Transplant recipients are usually allowed to resume sexual relations as soon as they feel ready. However, recovery of sexual functioning is related to the ability to overcome these negative feelings.

Serious illness and major surgery can leave many individuals with the idea that physical limitations mean that they are sexually unattractive. Men's symptoms might include inability to achieve or maintain an erection. Sometimes premature ejaculation or none at all can be a problem. Women may have a decrease in vaginal fluid for lubrication, making intercourse painful. Some women complain of inability to have an orgasm.

Induced diabetes and medication side effects may produce low sex drive; physical limitations such as pain from your incision may require different positioning. Fatigue may require you to plan for time to engage in sexual intimacy.

Suggestions About Resuming Sexual Relations

- Choose a time when you are both rested and free from stress, perhaps early morning or after a nap. Select a familiar, peaceful setting where you will both be comfortable.
- Mutually satisfying sexual experiences between partners can serve to improve self-esteem; since the feeling supports the concept that one is attractive and valued by another person.

Physical Considerations

- It is recommended that since sex can be an aerobic activity, that you add a warm-up and cool-down into the activity. This could include seven to 10 minutes of fore play before intercourse and seven to 10 minutes of cuddling afterwards.
- If you are unable to lie flat, or become breathless, consider adding additional pillows to support your upper body.

- For six weeks, until your doctor tells you otherwise, avoid putting weight through your arms or onto your chest.
- You may want your partner to do the majority of the work involved with this activity.
- Remember to pace yourself; take breaks as indicated.
- Remember to ask questions to any staff member for clarification or more information.

Pregnancy

Some men and women may have questions about becoming pregnant after having a transplant. Unfortunately, little is known about how your immunosuppressive medications could affect a growing fetus.

Even though you may not be having regular menstrual periods, it is still possible to become pregnant. It is important to use birth control to avoid unwanted pregnancy. Pregnancy can increase the rate of rejection. The possibilities for serious immediate genetic complications, as well as the potential for life-threatening complications to children later in life (such as cancers, diabetes, etc...) are very real. However, recent studies may suggest that this is less risky if the man is the transplanted partner. Certainly, more study is needed in this area.

For this reason, The University of Michigan Transplant team **HIGHLY RECOMMENDS** that you take all precautions necessary to prevent any pregnancy. If you or your partner do become pregnant after your transplant, talk to your lung transplant doctor immediately.

Some acceptable methods of preventing pregnancy after transplant include:

- **Surgical sterilization:** Has proven to be highly successful in preventing pregnancy and is recommended.
- **Barrier methods:** Barriers including condoms, diaphragms and sponges have been proven to be successful in preventing pregnancy.

Sexually Transmitted Diseases (STDs)

As with all sexually active people, you should be concerned about preventing any sexually transmitted disease. This is especially important for people who have received an organ transplant and are immunosuppressed. You are more at risk to developing serious side effects from any infection. Unprotected oral-genital sex should also be avoided if there are any oral cuts or genital sores. If you become aware your partner has tested positive for an STD or you notice any symptoms, contact your medical provider immediately.

