

Living With Your Transplant

Your Daily Routine

- Record blood sugars if directed.
- Take your medicines as directed by your transplant team. NEVER skip a dose of immunosuppressive medicine. Call your transplant coordinator if you miss a dose.
- Shower daily. Do not take a bath until your incision is completely healed and you have no drainage tubes in place.
- Frequently wash your hands with soap and warm water, especially before preparing food, after using the bathroom or after touching soiled linens or clothes. Lather well, rubbing your hands together and cleaning all surfaces, including under the fingernail beds.
- Stay active (see Activity section).

Sun Exposure

Transplant patients are at greater risk of developing skin and lip cancers because of your anti-rejection medicine. You must always protect yourself from ultraviolet rays of the sun that cause skin cancer.

To decrease your risk of skin cancer you should always:

- Use a sunscreen lotion with skin protective factor (SPF) rated 30 or greater.
- Wear a hat, long sleeves and slacks when outdoors, unless you are wearing sunscreen.
- Don't forget to put sunscreen on your face, neck and hands. Reapply often.

Alcoholic Beverages

IF YOUR DIAGNOSIS IS ALCOHOLIC LIVER DISEASE YOU SHOULD NOT DRINK ALCOHOL FOLLOWING TRANSPLANTATION. Drinking beer, wine and liquor may damage your liver. Medicines such as tacrolimus, cyclosporine, mycophenolate and trimethoprim-sulfamethoxazole are broken down by the liver and, if combined with alcohol, could harm your liver.

For patients whose liver disease is not caused by drugs or alcohol, alcoholic beverages are allowed only for special occasions and in very limited quantity.

Smoking

The Surgeon General has decided that both active and passive smoking can be harmful to your health. Smoking is a risk factor for many diseases. It will increase your risk for developing coronary artery disease and add to your already increased risk for osteoporosis, development of cancers and lung disease. Smoking marijuana can cause a serious fungal lung infection. DO NOT SMOKE. Ask your spouse and friends not to smoke when you are around. If you need further assistance to quit smoking, call your local doctor or the transplant team. There are many options available to help you stop smoking.

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Resources

<http://www.transplantliving.org/after-the-transplant/pregnancy/>

http://www.alpha1advocacy.org/transplant_pregnancy_web.html

<http://www.itns.org/patienteducation.html>

National Transplantation Pregnancy Registry
3401 N. Broad Street
Parkinson Pavilion, Suite #100
Philadelphia, PA 19140
Toll free: 1-877-955-NTPR (6877)
Fax: 215-707-8894
NTPR.Registry@temple.edu

www.temple.edu/NTPR

Vacation and Travel

Travel can lead you to many new and exciting places. Travel can also lead to new environments filled with potential challenges for the immune-compromised individual. Be alert and act wisely. When taking public transportation, remember there will be many people traveling with you, sometimes in close proximity such as on buses, trains and planes. Air is re-circulated in these environments, which means you may be breathing air containing viruses and bacteria from other passengers. Good hand washing is very important at all times, but especially when you travel.

When you are changing time zones, you may need to adjust your dosing time based on your new time zone.

Travel outside the United States can present health risks to people whether or not they are taking anti-rejection medications. Therefore, it is wise for you to take extra precautions. It is best to contact your local Department of Health and Human Services for recommendations on vaccinations or medicines that may be needed for the country where you are traveling. Remember do not take any live vaccinations.

- Contact your transplant coordinator if you will need to adjust your lab schedule or clinic appointment while you are gone.
- Be sure that you have enough medicines during your trip before leaving on your trip.
- Pack your medicines in your carry-on baggage.

Medicines

Contact your transplant doctor or coordinator before starting any new medicines that a primary care doctor or a referring doctor might order. There might be known side effects with your immune suppression medicine that can be avoided.

Keep an up-to-date medicine list and bring it with you to all clinic visits.

Contact your transplant coordinator if your insurance coverage changes or requires you to use generic anti-rejection medications. The transplant team may need to change your lab schedule if your medication is changed.

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Health Maintenance Following Transplant

Appropriate and timely health care screening is important for everyone, but it is even more important if you have received an organ transplant. Anti-rejection medicines can increase your cancer risk. To make sure of continued good health, we ask that you have the following screenings with the appropriate health care provider at the recommended intervals.

Primary Care

Primary care providers are health care professionals who provide general care. They may be family medicine or internal medicine doctors, nurse practitioners or doctor assistants. You should see them for:

- Medical history and physical exam yearly
- Blood pressure check yearly or more frequently as needed
- Diabetes screening yearly
- Lipid watching (cholesterol check) yearly
- Bone health watching (Dexascan) every 2 to 4 years based on previous results and/or bone therapy
- Obesity

Cancer Screening

Skin cancer is a common cancer. Risk factors include medicines and exposure to sunlight. Recommendations for prevention include:

- SPF of a least 30 with any sun exposure
- Annual skin check

- Report any skin lesions (review for the ABCDs of skin cancer):
- Asymmetry or irregular shape of lesion
- Border of lesion appears abnormal
- Color of lesion has differences
- The width is greater than the head of an eraser

Colon cancer is another common cancer. The American Gastroenterology Guidelines suggests screening and diagnostic colonoscopy for any one over the age of 50 and at regular intervals from then on. This test can be done by your local gastroenterologist. Patients with certain high risk diseases may require more frequent testing.

Breast cancer experts recommend women have a mammogram annually beginning at age 40. Women should have a clinical breast exam by a clinical gynecologist every 3 years from age 20 to 30 and annually after age 40. Breast self-exam is recommended monthly beginning at age 20.

Patients who are at increased risk for breast cancer include:

- Two or more relatives with breast or ovarian cancer
- Breast cancer occurring before age 50 in an affected relative
- Relatives with both breast cancer and ovarian cancer
- Male relatives with breast cancer

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Prostate has no set testing guidelines. Recommendations include prostate specific antigen (PSA) testing at age 50 (age 45 for African Americans).

Gynecological cancer screening should include once a year pelvic exam and Pap test.

Other Health Care

It is important to take care of your teeth and eyes as well. Follow the recommendations below:

- Dentist, at least yearly
- Eye exam, every 2 to 4 years after age 40 and every 2 years after age 60

The studies and time frames listed are recommendations. Your individual health history may call for more frequent testing. Please ask your primary care provider to contact us for any concerns or questions at **402.559.5000**.

We Are Here to Help

It is important to be seen regularly by the transplant doctor team. We recommend returning to the Transplant Center at least once a year.

We care about you and want your transplanted organ to last for many years. Although you will be seeing primary care doctors, please notify the transplant office if a serious diagnosis is made, if you have symptoms of infection or there is concern about your organ function.

Please share this information with all the members of your health care team. We feel these recommendations are very important to your overall long-term health.

Please update us with any address or telephone changes.

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Guidelines to Writing Your Donor Family Letter

Anonymity

Donor families are offered the opportunity to save a life through organ donation, while their identity remains anonymous. Each family's loss is personal. How family members cope with their loss may decide their receptiveness to correspond with recipient families.

Our intention in encouraging donor and recipient correspondence is to provide support to families experiencing the grieving process and to express gratitude to donor families. We are encouraged by the potential emotionally healing benefits of correspondence, but we are careful to protect the confidentiality of those who do not wish to participate. Therefore, we initially limit correspondence to an anonymous format.

Letter Content

The decision to write your donor family is a very personal one. Sometimes, transplant recipients choose to write to donor families to express their gratitude. If you find it is too difficult to write a letter, a simple card can also be uplifting to the family. We have made suggestions for the content that might be included in your correspondence. These suggestions are only meant to be a guideline and are not meant to dictate what you should include in your letter.

To keep the correspondence confidential, we do ask that you exclude the following: last name, address, city, state, phone number, email address and any reference to Nebraska Medicine. Please include any information that might help the donor family "picture" you.

This letter will more than likely be read and shared with many donor family members. Care should be considered with the amount of negative information included. Even though the outcomes of some transplants are not as successful as others, this does not diminish the gift. We are still indebted to these gracious donor families whose intentions were to save a life.

Examples include:

- Address the letter "Dear Donor Family"
- Recognize the donor family's gift and include thanks for this gift
- If you wish, express your condolences for their loss
- Use your first name or nickname only; do not include your last name
- If you choose to leave out your first name, simply sign as a grateful recipient, liver and/or intestinal recipient, friend, etc.
- Your age and gender
- Your family situation such as marital status, children or grandchildren
- Your hobbies or interests
- Your job or occupation. Do not mention your employer's name or recognizable status or position.

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- Explain what has happened in your life since your transplant. Did you return to school, accept a new job, have children, travel?
- Your current physical condition
- Whether you would be open to future correspondence from the donor family
- Since the religion of the donor family is unknown, please consider this if you include religious comments
- Other family members may include their own letters to the donor family
- Be sensitive to correspondence around the holidays, anniversary of donor's death, etc.
- Place a separate piece of paper with your full name and the date of your transplant in this unsealed envelope.
- Place the unsealed envelope into another envelope addressed to:

**Donate Life Services
Nebraska Medicine
988136 Nebraska Medical Center
Omaha, NE 68198-8136**

Mailing Your Letter

Allow extra mailing time. Your letter is first reviewed by a Donate Life Services coordinator at Nebraska Medicine to ensure confidentiality guidelines have been observed. Next, it is mailed to the organ procurement organization (OPO) that worked with your donor's family. The OPO will then forward the letter to the donor family.

Although most families are happy to receive a letter from the recipient, every donor family is given the option of not reading the recipient's letter. Some donor families move and cannot be contacted. If your letter is not able to be forwarded, you will be called.

Where Should I Send My Letter?

- Place your card or letter in the unsealed envelope. Please do not place a stamp, write your return address or your full name on this envelope.

Will I Hear from the Donor's Family?

You may or may not hear from the donor's family. Some donor families have said writing about their loved one and their decision to donate helps them in the grieving process. Even though they are comfortable with their decision to donate, other families prefer privacy and choose not to write the recipients. Many donor families will wait until they have heard from a recipient before writing to that person.

The correspondence should be family-driven. Correspondence may be a one-direction, one-time letter of thanks or it could evolve into a series of reciprocal letters between donor family and recipient. Each relationship will be unique. It is important to respect the comfort level of the donor family with timing and frequency of sending letters.

If you would like further assistance in writing your donor family, please feel free to contact us at 800-956-7426 or 402-559-9566.