

Living with a new heart

Your daily routine

Take your vital signs (blood pressure, temperature, heart rate) routinely every morning and every evening as directed by your transplant team. Record them daily in your logbook and bring to biopsy and clinic visits.

Weigh daily, first thing in the morning after going to the bathroom and before eating. Use the same scale and wear the same amount of clothing. Record in logbook.

Record blood sugars as directed.

Take your medicines as directed by your transplant team. **NEVER** skip a dose of your immunosuppressive medication. Call your transplant coordinator if you miss a dose.

Bathe or shower daily using a mild soap.

If you have dry skin, apply a mild skin lotion after bathing.

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 nail bed.

Stay active (See Exercise Chapter).

Promoting Emotional Wellness After Transplant

- *Set small, easily achievable goals each day and keep track of them on a chart. Be creative with colors and designs to make it fun.*
- *Reward completion of goals with self-nurturing behaviors such as relaxation, listening to music, engaging in arts/crafts or other hobbies, or spending time outside.*
- *Engage in spiritually uplifting behaviors such as reading motivational quotes, inspirational books, time outdoors, or utilizing church support.*
- *If feeling stressed or down, remind yourself that this is a recovery period of transition and you will not always feel this way.*
- *If thinking about the past leads to low mood or frustration, focus on the future. Imagine yourself successfully achieving your goals and being involved in fun activities.*
- *Engage in fantasy about a place you'd like to visit or a fun experience. This can re-energize the mind and improve mood and outlook.*
- *Talk to your emotional support network daily about your emotions. Use "I feel..." statements to convey your stress, worry, fear, frustration, anger, etc.*

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Sexual activity

You may resume sexual activity after your transplant surgery. How quickly you return to your usual patterns will depend mostly on your recovery progress. Your sexual functioning may be affected by your transplantation and/or certain medications. Some people avoid sexual activity because they are afraid of rejection or of infection. If you have any of these fears, you may want to check with your transplant team. If you are sexually active and do not have a steady sexual partner, you must use condoms to reduce the risk of sexually transmitted diseases such as AIDS, syphilis, herpes, hepatitis or gonorrhea. You must use contraception to prevent unplanned pregnancy also. Don't be afraid to ask your doctor, nurse or heart failure coordinator questions about this while you are hospitalized or during your clinic visits.

Returning to work or school

One of the goals of our transplant program is to help patients return to work when they are physically and emotionally ready. Returning to work or school must be discussed with your transplant team. They will help determine your readiness to return. Your transplant doctor will tell you when you may return. The time frame will depend on many factors including your recovery and the type of work you perform.

Driving

You will not be allowed to drive after your transplant until you are released by your transplant team. Ask your transplant surgeon about driving when you have your first follow-up visit.

Sun exposure

Transplant patients have more risk of developing skin and lip cancers. Besides suppressing your body's ability to attack your new heart, the immunosuppressive medications also suppress the body's ability to recognize and destroy abnormal cells. Since the risk increases over time, you must always protect yourself from the ultraviolet rays of the sun that cause skin cancer.

- *Avoid midday sun (10 a.m. to 3 p.m.) when ultraviolet rays are strongest.*
- *Wear a hat, long sleeves and slacks when outdoors, unless you are wearing sunscreen.*
- *Use a sunscreen lotion with skin protective factor (SPF) rated 15 or greater.*
- *Use sunscreen lotion EVERY DAY (rain or shine) and put them on any areas not covered. Don't forget face, neck and hands. Reapply as needed.*

Acne

Prednisone, cyclosporine and rapamune can cause acne. To lessen skin problems:

- *Keep your skin as clean and oil free as possible.*
- *Use a wash cloth and mild soap.*
- *Make an appointment with a dermatologist if acne becomes a problem.*

Cuts and scratches

Use an electric razor to avoid cuts while shaving. Wash minor cuts and scratches daily with soap and water. For large cuts, see your doctor right away.

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Hair care

Prednisone will probably change the condition of your hair. Permanent hair dyes, tints, wave lotions and bleach may cause your hair to become brittle and break. It is recommended to wait until the prednisone is less than 10 mg daily before treating your hair. Tell your hairstylist you are taking prednisone and use a good conditioner.

Alcoholic beverages

Drinking beer, wine and liquor may damage your liver. Medications such as tacrolimus, cyclosporine, mycophenolate and trimethoprim-sulfamethoxazole are broken down by the liver and, if combined with alcohol, could harm your liver. Call your transplant team for advice.

Smoking

The Surgeon General of the United States has determined 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, damaging your new heart and add to your already increased risk for osteoporosis, development of cancers and lung disease. **DO NOT SMOKE.** Ask your friends/spouse not to smoke when you are around. If you need further assistance to quit smoking **CALL** the transplant team. There are many options available to help you stop smoking.

Pregnancy

Pregnancy after heart transplantation is considered a high-risk condition. You need to carefully consider this risk to your life and the baby's life. You should discuss children and birth

control options with your transplant team. Men with heart transplants have been able to father children. Because of the medications that you take, it is important to discuss the possible risks to the baby with your transplant team.

Vacation and travel

Travel can lead you to many new and exciting places as well as to new environments filled with potential challenges for the immunocompromised individual.

Be alert and behave wisely. When taking public transportation, remember there will be many people traveling with you, sometimes in close proximity such as buses, trains and planes. Air is recirculated in these environments which means that you may be breathing air containing viruses and bacteria from other passengers. For the first year after transplantation when your immunosuppression is at its highest, it is recommended that you avoid mass transportation as much as possible. If you decide to travel, it is advisable to wear a facemask to filter the air as much as possible. You may wish to continue this practice on long journeys on planes or trains. Travel can take you across several time changes that can affect when you take your medications. For the first day, keep your watch set on your own time zone and take your medication as usual. Then begin to reset your watch by an hour or two every day to the time zone in which you have traveled. Medications should be taken within an hour of the prescribed time. When you are changing your time zones, keep this in mind. Travel outside the United States can present health risks to individuals whether or not they are

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immunocompromised. Therefore, it is wise for you to take extra precautions. It is best to contact your transplant coordinator or physician to discuss the area you plan to visit. Your transplant team can advise you on contacts at a transplant center in the area whenever possible. They can also advise you on how to obtain information on current health risks for the area in which you are planning to travel. For instance, if you are planning to visit South America, there are several transplant centers throughout that continent and we can contact the Centers for Disease Control (CDC) and the State Department which have weekly updates on infectious outbreaks in any city or country in the world as well as the need for vaccinations and other preventive measures. Contact your transplant coordinator or physician to help determine if you will need any medications or vaccinations before leaving on your trip.

BEFORE MY HEART TRANSPLANT IT WAS A MAJOR EFFORT JUST TO GET OUT OF BED, GET DRESSED AND TRY TO DO SOME WALKING. NOW I GET UP EARLIER EVERY DAY JUST TO ENJOY LIFE.

– Nebraska Medicine patient

Medications

Your transplant team recommends you carry identification with you at all times that you are a transplant patient. In addition, you should always carry an updated medication list with you. You may ask your transplant coordinator about how

to obtain a medical alert bracelet or you may go online at www.IdentifyYourself.com.

Please contact your transplant doctor or coordinator prior to starting any new medications that a primary care doctor or a referring doctor might order. There might be unknown side effects with your immune suppression medication that can be avoided. Also, there is a medication called **adenosine** that is given in certain types of stress tests as well as to slow down fast heart rhythms. Please inform any medical personnel that want to use adenosine for a fast heart rhythm or an adenosine stress test; they should monitor your heart closely and consider decreasing the initial dose. Read more about denervation in the Surgery chapter. Please keep an up-to-date medication list and bring it with you to all clinic appointments and biopsies.

Understanding Your Emotions After Transplant

Most people experience some symptoms of depression or anxiety which may include:

- *Feeling sad, angry, anxious or easily overwhelmed*
- *Fear of death*
- *Persistent worry*
- *Guilty feelings*
- *Crying Frequently or easily*
- *Being unable to focus or concentrate*
- *Not sleeping well, sleeping too much, or being unable to fall asleep*
- *Changes in mood*
- *Changes in appetite*
- *Losing interest in health activities and relationships you used to enjoy*

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If these symptoms are bothersome, distracting or interfere with your relationships and ability to manage daily tasks, talk to your coordinator, physician, or mental health provider for assistance.

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 determine their receptiveness to correspond with recipient families. Our intention is to provide support to families experiencing the grieving process and to provide the opportunity for recipients to express their gratitude to the 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 that 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 your decision to contact the donor family. However, if you write, to keep the correspondence confidential, we do ask that you exclude the following: last name, address, city, state, phone number, e-mail 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 omit your first name, simply sign: a grateful recipient, heart recipient, friend, etc.
- Your age and gender
- Your family situation such as marital status, children or grandchildren

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- Your hobbies or interests
- Your job or occupation (Do not mention your employer's name or recognizable status or position.)
- 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
- If 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 holidays, anniversary of donor's death, etc.

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 unable to be forwarded, you will be notified.

Whom Do I Send My Letter To?

- Place your card or letter in an unsealed envelope. Please do not place a stamp, write your return address or your full name on this envelope.
- 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
3860 Leavenworth
Omaha, NE 68105-8136**

Will I Hear From The Donor's Family?

You may or may not hear from the donor's family. Some donor families have said that writing about their loved one and their decision to donate helps them in their 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 in regard to timing and frequency of sending letters.