

Living with Your Transplant

Your Daily Routine

- Take your vital signs (blood pressure, temperature, heart rate) at the same time every day. Take them in the morning and at night, as directed by your transplant team. Write them every day in your home care flow sheet. Bring the book with you to your clinic visits
- Weigh yourself every day, first thing in the morning after going to the bathroom and before eating. Use the same scale and wear the same amount of clothing. The scale should be on a hard level surface to get an accurate reading. Record your weight in your home care flow sheet
- Record blood sugars as directed. Follow up with your diabetes doctor if you have any concerns
- 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 using a mild soap and water
- Good hand washing is important. Wash your hands with soap and warm water. Lather well, rubbing your hands together and cleaning all surfaces including under the fingernail beds. Always wash hands before preparing food or eating food. Wash hands after using the bathroom or after touching soiled linens or clothes

Sun Exposure

Transplant patients are more at risk of developing skin and lip cancers. Since the risk increases over time, you must always protect yourself from ultraviolet rays of the sun that cause skin cancer.

Use sunscreen every day that has a skin protective factor (SPF) rated 15 or greater. Remember to put sunscreen on your face, neck and hands, and re-apply as needed. Stay away from the mid-day 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.

Alcoholic Beverages

Alcoholic beverages are allowed. We recommend strict moderation for several reasons:

- 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
- Alcohol has the potential to change the way your liver breaks down the anti-rejection medicines and this could put you at risk to rejection

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- Alcoholic beverages also contain a large amount of calories
- Liquors and wines contain concentrated sweets

Tobacco Use

DO NOT SMOKE OR CHEW TOBACCO. 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 and add to your already increased risk for osteoporosis, development of cancers and lung disease. Smoking marijuana can cause serious fungal lung infections. Ask your family and friends 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

If you are thinking about getting pregnant after transplant, it is very important to talk to the transplant team, obstetrician and transplant coordinator. It is possible for women to become pregnant within a few months after transplant; however, it is best to wait at least one to two years. This allows time to make sure that the transplanted organ is functioning well and that anti-rejection medicine doses are

at maintenance level and stable. Some of the medicines to control rejection may cause birth defects. Contact your doctor before becoming pregnant.

If it has been one to two years since your transplant and you are thinking about having a baby, you should have:

- Stable levels of anti-rejection medicines
- Stable function of the transplanted organ
- Good kidney function
- Normal blood pressure or well-controlled high blood pressure
- Normal blood sugar levels or well-controlled diabetes
- Overall good health

Vacation and Travel

If you are planning extended travel, are leaving the country, or will miss getting labs done, please notify the transplant team.

When taking public transportation, remember there will be many people traveling with you, sometimes in close areas such as on buses, trains and planes. Air is recirculated in these places, which means you may be breathing air containing viruses and bacteria from other people. Good handwashing is very important at all times but especially when you travel.

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It is wise for you to be extra careful when traveling. It is best to contact your transplant team to discuss the area you plan to visit while traveling outside the U.S. They can also tell you on how to get information on current health risks for the area where you plan to travel. It is recommended that you schedule a traveler's health appointment at least 4 to 6 weeks before your trip. Nebraska Medicine Vaccine & Safe Travel Clinic has two locations in Omaha: Village Pointe, 110 N. 175th St., 402.596.4411, and at Midtown Clinic, 139 S. 40th St., 402.595.3939.

Contact your transplant coordinator or doctor to help determine if you will need any medicines or vaccinations before leaving on your trip.

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 you have continued good health, we ask that you have the following screenings with the appropriate health care provider at the recommended intervals.

Primary Care - Health Maintenance

Set appointments again with your referring kidney doctor. Primary care providers are health care professionals who provide general care. They may be family medicine or internal medicine doctors, nurse practitioners or doctor's assistants. You should see them for:

- Medical history and physical examination yearly based on your risk factor
- Blood pressure check yearly or more frequently as needed
- Diabetes screening
- Skin exam
- Lipid monitoring (cholesterol check) yearly
- Yearly stool screen for blood
- Colonoscopy every 5 years after the age of 50, unless previously abnormal or you have a family history of colon cancer
- Bone health monitoring (Dexascan) every 2 to 4 years based on previous results and/or bone therapy

Women

- Mammogram
- Breast exam
- Pelvic exam
- Pap test

Discuss your plan of care with your primary care provider.

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Men

- Prostate/testicular exam every 1 to 2 years if over the age of 40, then yearly after the age of 50
- Prostate Specific Antigen (PSA) lab test yearly after the age of 40

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

Your health history may cause you to have more frequent testing. Please ask your primary care provider to fax any abnormal results or results that concern you to the transplant office at **402.552.3030** or call **402.559.5000**.

Home Records

When you are discharged, a transplant nurse, nurse practitioner or doctor's assistant will instruct you on your schedule for follow-up lab tests. A letter will be sent to your local lab with instructions as well. If you are getting lab work done at a lab that is not part of Nebraska Medicine, we will provide you with tubes and mailers to take with you to your lab the first time you go. The tubes and mailers will be replaced by our lab as they are used.

Lab results may be recorded on your home care flow sheet. Make sure that you are fasting when your lab work is drawn so we can monitor your blood sugar results each time you have labs done. Also, do not take your transplant anti-rejection medicine until your lab work is done.

Weigh yourself daily. It is important to use the same scale and to weigh yourself at the same time each day. Record your weights.

Check your temperature every day and record it on the home care flow sheet. Report any temperature over 100.5°F or any persistent (over several days), low-grade temperature greater than 100°F.

Check your blood pressure every morning and at bedtime, and record it. Always check your blood pressure in the same position (lying, standing, sitting). If your blood pressure is higher than 160/95 for two days in a row, or lower than 110/65, please call the transplant office.

Blood pressure ranges for pediatric patients will vary depending on the age of the child. Please contact the pediatric nephrology team to provide the ranges for your child and write the information in the space below.

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Writing Your Donor Family Letter Guidelines

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 in encouraging donor and recipient correspondence 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 letter. These suggestions are only meant to be a guideline and are not meant to dictate what you should include in your letter. You may also call Donate Life Services for

additional information, 402.559.9566. However, to keep the correspondence confidential, do NOT include your 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. Be careful not to include negative information. 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, kidney recipient, friend, etc.
- Your age and gender
- Your family situation such as marital status, children or grandchildren
- Your hobbies or interests

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- 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 communication 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 communication 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 make sure confidentiality guidelines have been met. 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.

How Do I Send My Letter?

1. Place your card or letter in an unsealed envelope.
2. **DO NOT** place a stamp, write your return address or your full name on this envelope.
3. Place a separate piece of paper with your full name and the date of your transplant in this unsealed envelope.
4. Place the unsealed envelope into another envelope addressed to:

**Donate Life Services
Nebraska Medicine
3860 Leavenworth St.
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 communication should be family driven. Communication may be a one-direction, one-time letter of thanks, or it could grow into a series of mutual letters between donor family and recipient. Each relationship will be unique. It

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is important to respect the comfort level of the donor family in regard to timing and frequency of sending letters.

We have included a few sample letters from grateful recipients. If you have any further questions regarding donor family correspondence, or you would like further assistance in writing your donor family, please feel free to contact us at 800.956.7426 or 402.559.9566.

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Sample Letter

Dear Donor Family,

We are writing to thank you for making the unselfish decision to donate life in order that our daughter, Allison, could live. She received a liver, small bowel and pancreas from your loved one. The transplant surgery went well and she had a good recovery. She was hospitalized for about three weeks as an inpatient and then another five weeks in outpatient care.

Allison received the transplant just three weeks before her 23rd birthday. She had a condition called short bowel syndrome and since birth has received the majority of her nutrition through a central intravenous catheter. Over the years, this IV nutrition caused liver damage, and more recently it led to life-threatening central IV line infections.

Despite her medical issues, Allison has always been a very optimistic and involved person. While in high school, she was very active in school activities and 4-H and also played piano and organ at our church and area churches. She has been attending college with a major in early childhood education. She was supposed to graduate in December 2006, but she had to postpone college commitments due to a lengthy hospital stay last fall. In January, she was scheduled to start a practicum as a child-life specialist at a hospital pediatric unit. Since her recovery has progressed so well, she was given permission to complete that during the month of April. She plans to graduate in May. Her career goal is to become a certified child life specialist and work in a hospital pediatric unit.

Allison has an older brother, Curtis; younger brother, Ryan; and younger sister, Andrea. We live on a farm and our children attended a small town school. They've been very involved in school, community, church and 4-H activities. Family times are very important to us all.

You are a very special family for sharing your loved one's life in order that Allison could live. It is our hope that we can continue to write and share our lives with you, as we hope you will write and share about yourselves and your loved one. We, and many others in our extended family and community, have prayed for your family during this time of loss.

Our sincere thanks and love,

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Sample Letter

Dear Donor Family,

We can't imagine the pain and sorrow you have experienced since the death of your loved one. My husband and I extend our sincere sympathy to you and your entire family. It is also our hope that the following letter is of some comfort.

Twenty seven years ago, about this time of year, I was diagnosed with Type I diabetes. Since the age of 4 I endured daily injections, constant blood monitoring, timely meals and complications related to this disease. Living with diabetes became a way of life for me and those around me.

With a lot of determination, plus the love and support of family and friends, my childhood was much like all of my friends. I was active in sports and loved babysitting. As long as I can remember, my dream was to become a teacher. I worked hard in college, graduated magna cum laude with a Bachelor of Science degree in elementary education with an endorsement in coaching. The day I received the phone call offering me the third-grade position and assistant volleyball coach position at a public school nearby was one of the happiest in my life.

Eight years later, I am still at the same school doing what I love. During that time, I also met and married the man of my dreams. Chris is a journeyman lineman with a local power company and is also an active fireman and EMT in our community. He is an avid hunter who loves the outdoors. When we have time, we enjoy being with our nieces and nephews and working in our yard and flower gardens.

During 2002, I began experiencing complications related to the diabetes, and I was devastated to learn my kidney function was decreasing. In May 2005, it became evident that a transplant was inevitable and the process was begun. As a result of the required evaluation, coronary artery disease was discovered and it was determined that I would need a heart stent. We were also warned that the heart catheter, required for the procedure, may further reduce the function of my kidneys. To make a long story short, I spent the summer recovering from heart surgery and learning to do peritoneal dialysis at home. Without the love and support of my husband and our families, I would not have been able to return to my next class of third graders that fall, which by the grace of God I was able to do!

Fast forward two years and another very special phone call; this one bittersweet. I spent another summer recovering from the life-giving surgery. It has been a little over five months since I have been insulin free. No daily injections, no finger pricks to test blood sugar. No hooking up to a machine each night to cleanse my body of toxins. No calling in sick at least once a week. I can eat whatever and whenever I want. I can walk stairs and not be out of breath. My feet don't hurt. My ankles and face aren't swollen. I have energy at the end of the day. It is hard to believe that a phone call can make such a difference in someone's life, but it did!

I have been given a second chance and enjoy a quality of life that I haven't had in a long time... I am forever grateful! There was a time when I didn't know if I would be able to continue teaching. I plan to begin my Master's degree in education this next spring. My husband and I have begun to think about the possibility of adopting a child. There is once again "hope" in our lives... all because of someone very special. It is said that time heals all things... and it is our wish that each new day brings you peace and renewed strength.

Very sincerely,

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Sample Letter

Dear Donor Family,

My name is Maddy and I'm 9 years old. I got a liver from your loved one. I needed a liver transplant because I had Wilson's disease. Thank you for my new liver. I would have died without a new liver. I didn't want to die because I wanted to be with my family.

I'm sorry that you are feeling sad right now. I know you miss your loved one. I think about you a lot.

I have a little sister, Olivia. She is 7 years old and she's very funny. I like soccer and my favorite holidays are Christmas and Thanksgiving. I have short blonde hair and blue eyes.

I never felt better before and I will take care of my liver.

Love,