

Living With Your Transplant

Your Daily Routine

- Take your vital signs (BP, temperature, heart rate) routinely every morning and every evening as directed by your transplant team. Record them daily in your logbook and bring to 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 pages provided.
- Record blood sugars as directed.
- Take your medicines as directed by your transplant team. NEVER skip a dose of immunosuppressive medication. Call your transplant coordinator if you miss a dose.
- Shower daily using a mild soap.
- 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 have more risk of developing skin and lip cancers. Besides suppressing your body's ability to attack your new kidney and/or pancreas, 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 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 30 or greater.
- Use sunscreen lotion EVERY DAY (rain or shine) and put it on any areas not covered.
- Don't forget to put sunscreen on your face, neck and hands. Reapply as needed.

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. Alcoholic beverages are permitted; however, we recommend strict moderation for several reasons. Alcoholic beverages contain a large amount of calories. Liquors and wines contain concentrated sweets. Alcohol has the potential to change the way your liver breaks down the anti-rejection medications and this could predispose you to rejection.

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

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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 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 discuss this with 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 medication doses are at maintenance level and stable.

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 medications
- Stable function of the transplanted organ
- Good kidney and/or pancreas function
- Normal blood pressure or well-controlled high blood pressure
- Normal blood sugar levels or well-controlled diabetes
- Overall good health

A brochure is available in the transplant clinic or through your transplant coordinator that can answer many of your questions about pregnancy after transplant for women and men. Please ask your coordinator or clinic nurse for a copy. It is also very important to discuss with the transplant physicians your decision to pursue pregnancy.

For more information:

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

www.alpha1advocacy.org/transplant_pregnancy_web.html

National Transplantation Pregnancy Registry
3401 N. Broad Street
Parkinson Pavilion, Suite #100
Philadelphia, PA 19140

Toll free: 1-877-955-NTPR (6877)

Fax: 215-963-0674

NTPR.Registry@temple.edu

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 on buses, trains and planes.

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Air is recirculated in these environments, which means you may be breathing air containing viruses and bacteria from other passengers. Good handwashing is very important at all times but especially when you travel.

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 where you have traveled. Medications should be taken within an hour of the prescribed time. When you are changing time zones, keep this in mind.

Travel outside the United States can present health risks to individuals whether or not they are 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 where you are planning to travel. For instance, if you are planning to visit South America, there are several transplant centers throughout that continent. We can also contact the Centers for Disease Control (CDC) and the State Department to receive 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.

Medications

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 known side effects with your immune suppression medication that can be avoided.

Please keep an up-to-date medication list and bring it with you to all clinic appointments.

Please contact your transplant coordinator if your insurance coverage changes or requires you to use generic immunosuppressants. Do not take generic immunosuppressants without the transplant team's approval.

Health Maintenance Following Transplant

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

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Primary Care

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

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

Women

- Mammogram baseline at 30 to 39, then yearly after the age of 40
- Breast exam yearly
- Self-breast exam monthly
- Pelvic exam yearly
- Pap smear yearly

Men

- Prostate/testicular exam every one to two 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 Healthcare

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

- Dentist (at least) yearly
- Eye exam every two to four years after age 40 and every two years after age 60

The studies and time frames listed are recommendations. Your individual health history may warrant 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**.

We're Here To Help

It is important to be seen regularly by the transplant physician team. We recommend returning to the Transplant Center at least once a year. It is also important to have an ultrasound of your native kidney and transplant kidney and/or pancreas every one to three years. We will arrange these studies at the time of your annual Transplant Center appointment.

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Because the anti-rejection medications can cause high cholesterol levels, bone disease, development of diabetes and high blood pressure, the transplant office may request extra tests to monitor these throughout the 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, you have symptoms of infection or there is concern about your organ function.

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

Home Records

The last section in this booklet will discuss your home recordkeeping. A Kidney/Pancreas Transplant Home Care Flow Sheet is included for your convenience.

When you are discharged, a transplant nurse, nurse practitioner or physician assistant will instruct you on your schedule for follow-up lab tests. A letter will be sent to your local laboratory with instructions as well. If you are getting lab work done at a laboratory 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 laboratory 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 tacrolimus (Prograf®), Rapamune or Cyclosporin until after 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 165/95 for two consecutive days, 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 transplant team to provide the ranges for your child and write the information in the space below.

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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 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 correspondence. These suggestions are only meant to be a guideline and are not meant to dictate what you should include in your letter. However, 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, kidney and/or pancreas 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
- 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

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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.

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 the 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,