Dear Ann Livers,

I want to write a letter to my deceased donor’s family but I don’t know where to start. My words just don’t seem to express my gratitude for such a wonderful gift.

It is not uncommon for transplant recipients and their families to have the desire to write a letter to their donor’s family as part of their healing process. It is also not uncommon for recipients to have the same difficulty as you are…getting started!

When I wrote my first letter to my donor family I had the same feelings as you…the words on the sheet of paper seemed so inadequate. My approach was to share my story with my donor’s family and, through that sharing, my gratitude for their gift of life became clear. Tell them whose life they have impacted. Share how transplant has changed your life and your family’s life. If appropriate, consider including messages from your family in your correspondence with your donor family. Family member’s insights are very special because they have been impacted significantly by this journey as well.

Communication between recipients and donor families is a very personal and private decision. Healing is occurring on both sides. For many donor families, their loved one’s death was totally unexpected….a stroke, a car accident, or a gunshot wound. I have come to learn over the years of my transplant experience, both personally and professionally, you are writing to a very special family that put their grief and pain aside long enough to think of other people during their time of loss. It is important to understand that they may have the same needs in their healing as we do…who is carrying on my loved one’s legacy? Your correspondence with them may assist in this process. You may not hear from your donor family depending on where they are in their grieving process however, your letter may provide the invitation for them to share their loved one’s story with you when they are ready.

University Transplant Center has a program to facilitate the process of contacting your donor family if and when you are ready to do this. Initially, communication between recipients and their donor families is done anonymously to allow for healing to occur on both sides. There are limitations to what information can be included in donor communication to maintain the privacy of both parties. You should not include your last name; your address, city or phone numbers; the location of the hospital where your transplant was performed; the name of your healthcare providers; and religious comments, since you do not know the religion of the donor family.

If writing a letter to your donor family is an important part of your recovery don’t hesitate to get assistance if you are having trouble with this. We have packets available to assist in this process. Consider talking to a fellow transplant recipient who has completed this process for mentoring in this area. If you have questions you can call 210-567-5777 and ask for the Organ Donor Family Coordinator.

Bruce Curry (Bilateral Lung, 2010) with donor’s mother (pictured on the left) and donor’s sister (pictured on the right).
In Memory

I would like to make a contribution of $________________________,

to further support the patients and programs at University Transplant Center (UTC).

Please select a Fund:

_____ Transplant Center Fund: helps support research, education, state-of-the-art facilities and surgical excellence at UTC.

_____ Transplant Endowment Fund: provides financial assistance to hundreds of UTC patients and their families who experience exceptional difficulties during the course of their treatment.

Donations can be mailed to:

University Health System Foundation | 903 W. Martin, MS 1-2 | San Antonio, TX 78207

University Transplant Center

4502 Medical Drive MS 18
San Antonio, TX 78229

Transplant Action Item

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Transplant Action Item
It is common for transplant recipients to have difficulty sleeping after transplant. The sleeping problems can vary from difficulty falling asleep, staying asleep, having restful sleep, or some combination of the three. On top of the pressures of everyday life, transplant recipients have many stressors such as recovering from surgery, physical pain, stimulating medications, and changes in sleep environment. A good night’s rest is crucial as it improves a transplant recipient’s daily functioning, quality of life, and work performance. Sleep deprivation can also affect one’s health if it persists, increasing the risk for depression, anxiety, hypertension, obesity, diabetes, and heart disorders. Before adding a sleep medication to your list, consider trying the following behavior modifications to help get a restful night’s sleep.

**Avoid stimulants.** Be aware of what you are putting into your body after lunch...especially what you drink. Drinks that contain caffeine will hang out in the body for a long time. Soda, coffee, tea, energy drinks, and certain flavored waters all contain a surprising amount of caffeine. Even decaf coffee contains caffeine...it just has LESS than regular coffee. In fact, some decaf coffees contain as much caffeine as a can of soda! For those of you who smoke or chew tobacco, on top of its numerous undesirable health effects, tobacco contains the stimulant nicotine.

Some medications can cause difficulty sleeping. Certain antidepressants, blood pressure drugs, asthma medications, and steroids will affect sleep. Talk to the Transplant Team to see if you are taking any medications that can cause difficulty sleeping and see if they can be switched to alternate dosing times or other medications less likely to affect sleep. Finally, for those who fancy a “nightcap”- beware! Although alcohol may help you fall asleep, it prevents restful sleep. Chances are you will wake up in the middle of the night or the next day feeling exhausted.

**Ban bedroom distractions.** Light, sound, and temperature are all important to a restful night’s sleep. If your bedroom is too bright, too loud, too hot or too cold, it may affect your sleep. Sleep tends to be the best in dark, quiet, cool environments. Therefore, limit light, noise, and hot temperatures in your bedroom. Also, remove as many electronic devices as possible. Electronics not only make it difficult to fall asleep, but the light and sound from them can also affect the quality of sleep.

**Consider the cause and fix it.** Figure out why you are having trouble sleeping at night. Are you hungry? Thirsty? Uncomfortable? Worried about something?

continued on next page
The ABC’s to getting some ZZZ’s (continued)

If you are hungry or thirsty, start having a filling dinner at least four hours before bed. If you are uncomfortable, adjust your body position or even your bedding to remove discomforts. If you are in pain, consider taking your prescription pain medication or non-prescription acetaminophen to help. Just remember to avoid NSAIDs such as ibuprofen (Motrin®) and naproxen (Aleve®). These are only two examples so if you are unsure which medications are “NSAIDs” call your transplant pharmacist for clarification. If you are worried or anxious, try your best to take care of all major concerns before falling asleep at night. Whatever you didn’t complete, make a list of what needs to be worked on the next day to reduce nighttime anxiety.

De-stress. What relaxes you? Whatever it is, make sure to include it in your nighttime routine. If you need some ideas, then try taking a warm bath a few hours before bed. The warm water will soothe aches and pains and the temperature drop after you finish the bath will signal the body to relax. Listen to low-volume relaxing sounds such as rain, music, or “white noise” ten minutes before bed to help you unwind. For those who like to watch TV or surf the web to help relax, studies have shown these activities may have the opposite effect and make it more difficult to sleep if done near bedtime.

Establish a regular sleep schedule. As simple as this may sound, it tends to be the most difficult. People want to stay up late and sleep in on their days off work making it difficult to maintain a schedule. Those who tend to wake up and go to sleep the same time everyday (or within an hour of their normal sleep time) tend to report better, more restful sleep.

If, after trying the above steps, you are still having difficulty sleeping, talk to your doctor and explain what type of difficulty you are having (falling asleep or staying asleep) and the time duration it has been happening. Your doctor may prescribe a trial period of medication to assist you with sleep.

If a medication helps, remember to only take the medication for a short period of time on the nights you are having difficulty sleeping, unless your physician or the Transplant Team tells you otherwise. Always make sure you are communicating with the Transplant Team to prevent adverse drug-to-drug interactions. They know you and will be able to guide you to the best possible option. If you are having trouble sleeping, it is critical to modify the things in your life that you have control over before adding another medication.


The Pediatric Kidney Transplant Program is back!

For the last 10 months, the team has worked tirelessly to see that children receive their lifesaving kidney transplant during the transition from one center to ours. Thirteen children have been transplanted so far, more than double the number hospital leaders were expecting.

Pictured from left to right: Dr. Greg Abrahamian (Surgeon), 2 year old Waymon Eason (Patient), Dr. Kimberly Irwin (Nephrologist), Mackenzie Johnson (Coordinator), Dr. Daniel Ranch (Nephrologist), Mickey Ryerson (CNO/COO Pediatric Clinical Services) and Dr. Mazen Arar (Nephrologist)
Love after transplant! Stephen Tyson (Bilateral Lung, 2011) was introduced to Larysa Sholom (Bilateral Lung, 2011) to provide moral support prior to her receiving a transplant. Since then, they climbed Enchanted Rock together, traveled to Kauai, Hawaii and are now engaged to be married. Larysa works at NuStar Energy and Stephen will be graduating from Trinity University next May with a degree in Political Science.

Nicole Di Meo (Bilateral Lung, 2012) enjoyed a restful and spiritual week retreat at the Laity Lodge with her two young children. They are pictured here enjoying some shaved ice to beat the summer heat. Another wonderful year and counting! Patsy Kimes (Kidney Donor, 1983) and Ken Klesel (Kidney Recipient, 1983) celebrated their 30th transplant anniversary on May 11, 2013.

If you have a picture of you “living your life” after transplant and would like to share with fellow recipients in future newsletters or on our social media sites, send it to Shanna.Puente@uhs-sa.com.

Do I have Drug Allergies?

Countless drug reactions are thought to be “allergies,” but in fact, they are not. A drug allergy is often confused with an adverse drug reaction (ADR). About two-thirds of individuals who visit a doctor for a reaction that is diagnosed as a “drug allergy” are actually not allergic. ADRs are common and can occur with almost any medication. True drug allergies are less common. However, an allergy and an ADR can cause similar effects.

What is the difference between a drug allergy and an ADR?
The distinction between a drug allergy and an ADR can be hard to determine. A drug allergy may occur the first time you take the medication or after you have taken several doses. An ADR is defined by the World Health Organization (WHO) as a noxious and unintended response to a drug that occurs at a dose that is normally used. These reactions can be categorized as “pseudo-allergies” because ADRs can resemble drug allergies but an immunological mechanism does not occur. These reactions are unpredictable and are caused by the effects of the drug on the body. This is different from a drug allergy which is caused by the body’s reaction to the drug.

The reactions that can be seen with both an ADR and a drug allergy can range in severity and may include: hives, itching of the skin or eyes, skin rash, swelling of the lips, tongue, or face and wheezing. In severe cases, a true drug allergy can also produce anaphylaxis, which causes the airways to tighten which leads to difficulty breathing and swallowing. Anaphylaxis is life-threatening and requires immediate medical attention.

If you have a true drug allergy to a medication, you will be allergic to all medications in that same class or category. It is important to explain to your doctor what, if any, allergic reaction you felt to a medication (example: penicillin - skin rash, ciprofloxacin: difficulty breathing, etc.).

How can you avoid drug allergies?
Avoid the drug that causes the reaction by alerting your medical providers. Keep a list of drug allergies and the type of allergic reactions you have to that medication in your wallet for easy reference and update it frequently. Also, consider wearing a medical identification bracelet or necklace that contains updated medication allergy information.

You are the only person who knows all the medications you take as well as your drug allergies. Be the link to all of the healthcare providers that take care of you. The more information you share with your healthcare providers, the safer your healthcare will be.

Wound Care Tips

Many of the incisions used in transplant are large and heal slower than non-transplant surgical patients because of the antirejection medications used after transplant, particularly prednisone®. Surgical wound care is an essential part of the immediate post-transplant regimen.

Monitor for signs of infection:
- Redness
- Swelling
- Foul smelling discharge-Pus (white, yellow or green in color, thicker than water)
- Warm to touch
- Oral tympanic temperature greater than 101.5°F

Wound care:
- Shower daily and gently clean your wound/incision with mild soap and water and pat dry…no need for heavy scrubbing.
- Do not submerge wound under water. That means no bathtubs, swimming pools, hot tubs, rivers, lakes or streams for 6 to 8 weeks or longer if wound is not completely healed.
- No heavy lifting/pushing/pulling
- Do not lift greater than 5-10 pounds. A gallon of milk weighs 7.2 pounds so use that as a gauge.
- No sit ups or push ups, sexual activity or anything that uses your abdominal muscles for 8 weeks.
- Do not apply any lotions, creams or ointments to your incision until instructed by your physician. Your wound will heal best if allowed to dry out.
- Staples, if used, will be removed in approximately 3 weeks after your last surgery.
- Seek medical attention if your wound comes apart at the skin, looks red and angry at the edges, or has pus or foul smelling drainage.

Walking outside your home, if possible, three times a day is highly encouraged but stay away from elyptical crossostrainers, bicycling, or any activity that rotates your abdomen. Additionally, be particularly careful when handling animals and plants. Any break in the skin needs to be thoroughly washed and watched closely for signs of infection. Wounds caused by animals, rose bush thorns, and things like garden mulch present a significant risk of infection to transplant recipients. Stay away from animals that may bite or scratch you, including your own, and always wear gardening gloves when working around thorny plants and soil.

by Christopher Poore, BSN, RN
Transplant Telemetry
Meet the new Transplant Advisory Council

The Transplant Advisory Council has been formed to address issues impacting University Transplant Center patients and their family members. It is an initiative by the Transplant Clinical Practice Performance Improvement Team that is meant to be:

1) Patient-Centric
2) An enhancement to the overall experience of transplant recipients and their families throughout the spectrum of care
3) Focused on clinical care, programs and policies
4) “Eyes and Ears” of the transplant program

The Council members meet quarterly to discuss improvement strategies and give feedback to University Transplant Center administrative and inpatient/outpatient clinical personnel. The Council membership includes: Terry Teaque (Bilateral Lungs, 2010 and Living-unrelated kidney, 2012) and his wife Nancy, Theresa Gomez (Living-related Kidney, 2012) and her son Matthew (Living Donor to his Mom), Angela Lewis (Bilateral Lungs, 2009) and Alfred Duke (Liver, 2011) and his wife Tonie.

The Council’s activities are focused around the Picker Institute and Harvard Medical School 8 Dimensions of Patient-Centered Care including 1) Respect for patients’ values, preferences and expressed needs, 2) Coordination and integration of care, 3) Information and education, 4) Physical comfort, 5) Emotional support and alleviation of fear and anxiety, 6) Involvement of family and friends, 7) Continuity and transition, and 8) Access to care.

The Council has played an active role in development of patient-centric practices for the new medical tower, outpatient clinic experience enhancement, transplant mentoring programs, and patient satisfaction initiatives. If you recognize one of them in your travels throughout the transplant center please stop and visit with them about your experiences with our program.

UTC STATS (1/1/2013 — 6/30/2013)

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Source: Scientific Registry of Transplant Recipients @ www.srtr.org

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The Outcomes Data above are the latest statistics available from the Scientific Registry of Transplant Recipients. Our transplant outcomes exceed, or are not significantly different from, the national and expected statistics. Please visit srtr.org for the latest statistical analyses and transplant program reports.