

a publication for transplant recipients and their families

renew

vol.2, no.1

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Healthy Living After Transplant It's All About Balance

Ryan Pflipsen, LCSW
Transplant Social Work

For most transplant recipients, a lot of attention has been placed on your physical health, however human beings are much more sophisticated than just the physical aspect! Much has been written on the body-mind-spirit components of each person and the impact on overall health when one or more of these parts are out of balance.

A strong social support system and healthy coping skills are essential to minimize stress during the transplant experience. We develop these skills throughout our life as we meet the challenges that come our way. Transplant not only puts these skills to the test but many times actually give recipients and their families the opportunity to learn new ones as well!

Before transplant, many patients are very sick, have a lot of uncertainties about their future, and require frequent treatments and hospitalizations. During this time it is common for people needing a transplant to take on a "sick role" and this can affect all aspects of their life and the relationships with family and friends. Frequently, this can cause some mental anguish and coping challenges as you attempt to adjust to your declining health.

Transplant is a life-changing event! As you recover from transplant and start to feel better physically, it will be important to continue to be aware of how you are feeling mentally and emotionally as well. If you begin to experience a wide range, dramatic, or sudden shift in emotions and feelings that are not normal for you, be very comfortable letting the University Transplant Center (UTC) team know so we can assess the situation and see how we can best support you during this time.

A great resource available to promoting your mental health and wellbeing is to get involved with a support group. A support group is typically a group of people that come together regularly to "support" one another and share in a common experience. In your case... transplant. These groups can meet



Dominique Michaud
Liver Transplant Recipient, 2007
and her husband, Robert

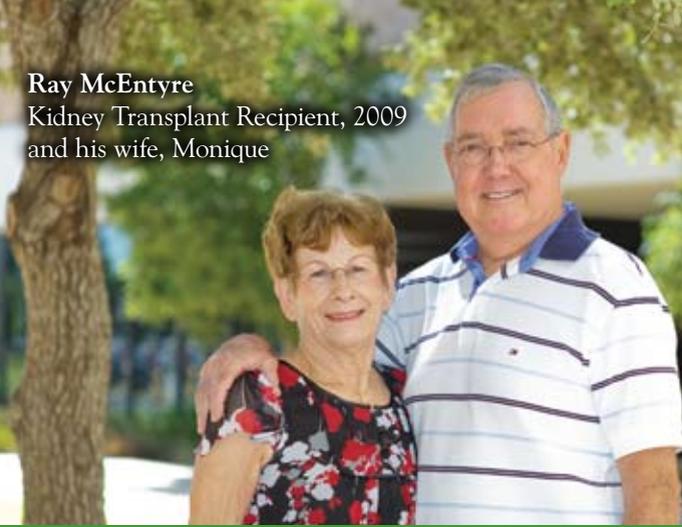
in person and in online forums or chat rooms and bring people together who may be geographically separated and not otherwise able to physically meet. UTC has a transplant support group called **Genesis**, that meets the 1st Tuesday of every month, at 12 Noon in the Foundation Room of University Hospital to share their transplant experience with each other.

At UTC our team of dedicated social workers are available to support you through every stage of transplant. Our unofficial motto is "once a transplant patient... always a transplant patient." If you have no one else to go to you can contact us. We can also suggest or refer you to social workers, clergy, counselors, psychologists or other mental health professionals. These experts are frequently in your own community to meet with you and follow your coping and adjustment post-transplant and support you and your family as well.

In the end, a successful recovery from a transplant is best achieved when you keep all aspects of your life in balance... body, mind and spirit.



Ray McEntyre
Kidney Transplant Recipient, 2009
and his wife, Monique



On Your Mark...

Get Set...

Medicare Open Enrollment Season Coming Up

Liz Cepeda, LMSW
UTC Social Worker

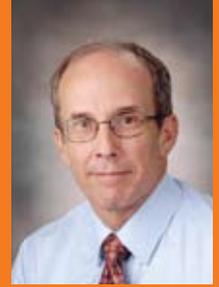
As summer comes to a close and we start preparing for school, cooler weather and even the holiday season, it is the time to begin preparing for Medicare Part D and Medicare Health Plan open enrollment season as well.

Medicare open enrollment is November 15 – Dec 31. It is during this time that patients may change Medicare Part D plans. Any changes made during this time period will take effect January 1, 2011. If you are considering changing plans please check with your transplant social worker to ensure that you understand how your changes will affect your benefits.

This is also the time of year that telemarketers start calling your home and hosting health fairs to enroll patients into Medicare Health Plans (also called Medicare Advantage and Medicare Part C). These plans **DO NOT** offer the same amount of coverage as traditional Medicare A and B. Enrolling in these plans may affect which doctors and pharmacies you use and also may affect how your drug plan coverage works, as well as any patient assistance programs in which you are currently enrolled. If you are contacted by anyone regarding changing your insurance coverage, please call your transplant center social worker immediately to obtain more information on how the plan will affect your insurance benefits.

Remember that maintaining good insurance coverage is your lifeline that allows you to access medical care and medications to maximize the life of your transplant. Contact your Social Worker at 210-567-5777 if you have any questions or need assistance in this process.

Dear
Ann Livers,



Q: I am a transplant recipient and was wondering if I could still be an organ donor.

A: Absolutely!! As transplant recipients, we and our families are probably more aware than most in the general population of the significant impact that organ donation has on a person's life. Because we have experienced, first hand, the impact of the "Gift of Life" in our lives, we can, and should, become strong advocates for organ donation to the people around us. What a better way than being an organ donor ourselves!

There are many myths and misperceptions about organ donation which give people pause when deciding to become an organ donor. Television shows, magazines, and even mainstream news media many times perpetuate these myths and misperceptions. Organ donation is open to all people, including those who have received an organ. Currently for transplant recipients, the organ that was transplanted would not be considered for re-transplant into another person.

Depending on the circumstances of our death, a decision will be made by appropriate medical professionals on whether or not our organs, tissue or eyes are suitable for donation. This will be based on our medical and social history and the events surrounding our death. With the recent advances in transplantation, many more people than ever before can be donors.

If you want to be a donor, sign a donor card and **discuss your wishes with your family**. By the time we are in a potential donor situation it is too late to have this conversation! Telling your family **NOW** that you want to be an organ and tissue donor is the best way to ensure that your wishes are carried out.

If you have not enrolled in the past three years you most likely are not enrolled in this system. To enroll as a donor in the State of Texas you can go to www.texasdear.org to register. The Spanish website is www.donevidatexas.org.



Exercise... It's a Good Thing

Bart Graves
Kidney Transplant Recipient, 2007

Marina Lang and Julie Aulner, *Physical Therapists*

Exercise is usually safe for anyone who has had a transplant. In fact, it is key to getting and staying healthy!

Before you start any activity, make sure that you check with your health care provider. This applies to anyone who has had a transplant but it is especially important for those who like rough and tumble sports like football or high-impact activities like jogging.

There are some general rules that can help make your exercise activities a success:

- Choose an activity that you like. Try out different types of activities and find out what you enjoy doing. You will have a better chance at success if you are doing something you like!
- Set goals and identify barriers. Make your exercise goals achievable. Start small and build on your successes. If you try to take on too much at a time, exercise will quickly become a "pain" and not enjoyable. Consider bringing someone else with you to your exercise activities for support or join a group.

- Listen to your body. If you are in pain or worn out after exercise, you have done too much. If you are fatigued, take a rest in a comfortable chair and plan better next time. Don't give up...the secret is to keep pushing yourself toward your exercise goals, but do it safely.

Once you have chosen what you will do for exercise, dress appropriately for the weather and wear protective footwear. Always warm-up before, and cool down after, exercise by stretching to get your muscles ready for increased activity.

Be cautious when swimming. Public pools and "swimming holes" may have bacteria that could be dangerous. Check with your doctor first. Avoid exercise outdoors when it is too hot or too cold. Depending on the climate or time of year, you may want to exercise early in the morning or indoors.

Remember, most people feel better after a transplant than they did before and have more energy to exercise. You don't have to be an NBA star like Sean Elliot (a kidney transplant recipient) or an Olympic Snowboard Champion like Chris Klug (a liver transplant recipient) to make exercise a part of your life.

UTC Stats (1/1/2010 – 6/30/2010)

Transplants: Kidney Liver Lung
 39 26 16

Outcomes Data:

Source: Statistical Registry of Transplant Recipients @ www.ustransplant.org

		Kidney	Liver	Lung
1-Year Graft Survival	Expected:	93.41	83.20	80.09
	Observed:	91.78	88.42	79.04
	National:	93.47	85.31	81.28
1-Year Patient Survival	Expected:	96.50	84.53	81.77
	Observed:	97.13	89.40	79.84
	National:	96.90	88.79	82.86

We are proud to share with our patients and partners that our transplant outcomes exceed, or are not significantly different from, the national and expected statistics. If you have questions about these statistics you can view them at the website above or contact us at 210-567-5777.

save the date

Genesis Support Group

1st Tuesday of the Month
12:30 – 1:30 PM
Foundation Room – 3rd Floor
University Hospital
Contact UTC Social Work Department
210-567-5777

TOSA Lights of Life Candle-Lighting Ceremony

Mission, TX - August 28
Austin, TX - October 23
San Antonio, TX - November 14
Contact Esmeralda "Mela" Perez
at TOSA
210-614-7030

San Antonio Walk for PKD

September 25, 2010
7:30 AM Register/9 AM Walk
Joske Pavilion
Brackenridge Park
San Antonio, TX
sanantoniowalk@pkdcure.org

Lone Star Transplant Games

October 2-3, 2010
San Antonio, TX
www.lonestartransplant.org

Ride for Life

Saturday, October 23, 2010
Temple, Texas

National Donor Sabbath

November 13-14, 2010
Contact Esmeralda "Mela" Perez
at TOSA
210-614-7030

Vital Alliance Run/Walk

November 20, 2010
Joske Pavilion
Brackenridge Park
San Antonio, TX
www.vitalalliancetexas.org

Special Note: Due to lack of grant funding this year, there will be no Gift of Life Patient Education Event this December.

You Are What You Eat



Kim Hendley
Registered Dietitian

The warm summer air has arrived bringing with it many outdoor activities, vacations, barbeques and cool clothing. Eating healthy should be a daily way of life to help you achieve or maintain a healthy weight, avoid future health complications and to offer an overall sense of feeling well and energized.

Although summer may bring to mind hot dogs, hamburgers, and chips and dips, you may be forgetting to include some of the very fresh, delicious food choices that are at their prime during this season. Try some of these tips below when preparing for your summer fun.

Make smart choices with your meats. It's a perfect time for grilling.

Try lean chicken or turkey kabobs rather than a hot dog. Grill burgers made with lean ground beef by choosing round or loin cuts of beef and trimming the fat off the edges.

Be careful with those side items. Limit foods such as casseroles, potato salad and coleslaw which often have high fat ingredients in them. Aim for all those fresh fruits and vegetables that are so flavorful and abundant during summer time—try grilling fresh fruits and vegetables or having them in mixed salads.

Approach appetizers with caution. Chips and dips can be very high in fat and sodium. Instead try fresh fruit kabobs, a relish tray with yogurt based dips or low fat dressings.

Limit those desserts. If you have saved room for dessert, try some healthier alternatives to cake, ice cream and pies. Fresh fruit smoothies made with fruit and low fat milk or yogurt is a simple treat with lots of flavor. You can also use fat free frozen yogurt to cool you down on those hot days! Fat free whipped toppings can be a great alternative to top off your treats rather than icing and heavy creams.

Stay hydrated.

Drink plenty of water during these hot days! Drinks such as cola's are not a good source of hydration and just add extra calories.

Use sensible portion sizes. Increase your portions of low calorie, healthy fruits and vegetables and limit the high calorie side items. Also choose a sensible 3 ounce piece of meat, aiming for the size of a deck of cards!

Traveling and eating. If you are traveling to all those great vacation spots, plan ahead and pack a cooler for lunch and some healthy snacks. Stopping at fast food restaurants or convenient stores along the way usually promote unhealthy eating. Stop and enjoy a picnic along the way instead!

Food Safety. Remember to be safe with your food and be sure it's kept at the proper temperature. Avoid those foods that have been basking in the summer sun all day!

So Long... Farewell...

After almost 10 years in the Transplant Clinic, Elvia Shope, LVN became Elvia Shope, RN! Elvia summed up her experience in the Transplant Center with the following:

"Many of you were my cheerleaders and I thank you for encouraging me along that journey. It has been a privilege to be one of your nurses and a part of your lives. I have enjoyed meeting great patients and their families and sharing your laughter and stories. I will miss every aspect of being there but most importantly I will miss all of you and your smiles. Taste Life – Goza la Vida."

Elvia has taken her new credentials as a Registered Nurse to work at Reeves Rehabilitation Center here at University Hospital.



lifescapes

Sandra Norwood (Bilateral Lungs, 2009) has published a book entitled *Breathing Easy* describing her amazing journey from illness to transplant. She is currently working on her second book focusing on life after transplant. More information can be found at www.lulu.com.



Heather Arocha (Liver, 2009) has started LVN training at Career Point College following a family trip to Colorado this summer. Heather has always been interested in a medical career and her transplant experience propelled her in the nursing direction. She plans to graduate in July 2011.



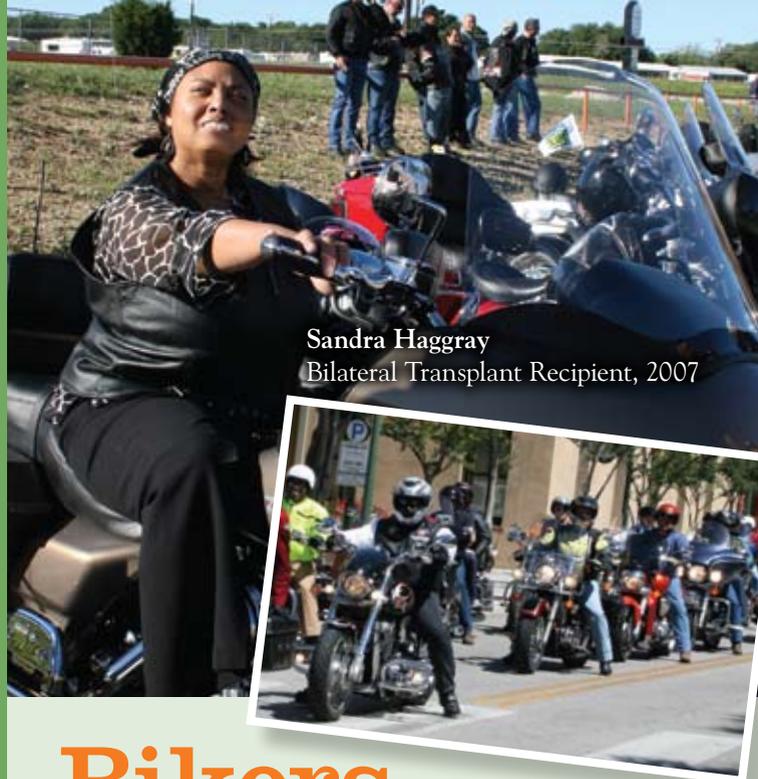
Charlie Joshua (Bilateral Lungs, 2008) is back to teaching nursing at the Career Point College LVN program. Charlie is a Registered Nurse and teaches Level 1 Fundamentals and does Clinical training in nursing facilities in San Antonio. Heather (above) and Charlie will be spending lots of quality time together during the next few months!!



Hollis Jeffries (Liver 2008) walked his daughter Amanda down the aisle for her marriage to Scott Egbert on March 7, 2009. Note Dad's proud smile and the green transplant bracelet on Amanda's arm!



If you have a story or picture of you "living your life" after transplant that you want to share with fellow recipients in future newsletters, send them to Darnell.Waun@uhs-sa.com.



Sandra Haggray
Bilateral Transplant Recipient, 2007

Bikers set their wheels in motion for life-saving cause

1st Annual Circle for Life Motorcycle Ride & Rally to raise awareness for organ and tissue donation

On April 24th more than 250 bikers came out to support the first annual Circle for Life Motorcycle Ride and Rally. The event which started at Javelina Harley-Davidson in Boerne and ended with an after party at Sunset Station signed up 200 donors on the Linda Dawson Donor Registry. The Circle for Life organization, with the support and resources of the University Transplant Center and UT Health Science Center Allograft Resources, has committed to raise awareness and education in the San Antonio community on organ, tissue and eye donation with an annual Motorcycle Rally.

The Circle for Life, a 501(c)(3) applied for organization, was founded by a group of prominent businessmen from San Antonio who are Harley riders and have strong ties and affiliation with Fiesta. The goal is to make the Circle for Life motorcycle rally an official sanctioned Fiesta Event that will occur annually and coincide with the Flambeau Parade. Their mission is to bring much needed awareness to organ and tissue donation in San Antonio and South Texas. More information is available on the Circle for Life web site at www.thecircleforlife.com. For more pictures on the event, please go to www.randygayportfolio.com/circleforlife2010.

**Please mark your calendars for the 2nd annual
"Circle for Life" Rally April 16, 2011.**

from the medicine cabinet

Heather H. Dobie, RPh, PharmD
Clinical Pharmacist



Don't Talk to Strangers!!!

We've all heard the adage, "Don't talk to strangers." Yet some transplant recipients don't heed this advice, particularly when it comes to their prescription insurance plan. They are contacted repeatedly and in various ways (by mail, by phone, and even at their door) by salespeople with the hopes of changing the patient's insurance to the plan that they sell. These frequent contacts in different formats make some patients feel pressured that they must change plans. Promises of the "same or better coverage" with "no extra co-pay" combined with warnings that "you must call before a certain date" make some people feel that they will be penalized if they don't act now.

Access to your transplant medications is essential to post-transplant health and most recipients need insurance to help with these costs. Don't feel pressured to make this important decision alone. Transplant recipients and family members are part of the "transplant family" at University Transplant Center (UTC). Our transplant social work team, with the assistance of our pharmacists, can help you make an informed decision that meets YOUR specific needs as a recipient.

The UTC Organ Transplant Manual advises: "**Before changing insurance companies, talk to a transplant team social worker to ensure good and continuous prescription benefit coverage.**" Despite this very specific recommendation, many patients change their prescription drug coverage plan WITHOUT consulting a transplant social worker first, and they may end up in a bind. They go to their regular pharmacy and are shocked to learn that their new plan either isn't accepted at their pharmacy or that their co-pays are higher than promised by the insurance agent when they talked.

A plan that might be good for your friend or neighbor may NOT be good for you. **Having a transplant means having very specific and different doctor and prescription needs than others.** The transplant social work team can consult with the transplant pharmacist to compare your current coverage to what you are considering changing to. The new plan may or may not be better for you and the combined expertise of your pharmacist and social worker can help you make an informed decision.

Changing insurance should not be a quick or uninformed decision. Your decision-making process should take into account many factors including what pharmacy you prefer to use. Some pharmacies may not be "in network" with some plans, meaning if you change plans, you might have to change pharmacies.

Many family members have good intentions to help patients with this insurance review process. If you want family members involved in this decision, make sure they are researching the facts with a social worker's help. These professionals can help you think of important factors that you or family members may not have considered.

One final thought: **Don't talk to strangers and make a change about prescription coverage without consulting your Transplant Team first**—they know you and your medical and prescription needs better than anyone else!

renew

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