

For Those Who Give and Grieve



A quarterly newsletter for donor families, published by the National Donor Family Council of the National Kidney Foundation, to offer information about grief and support.

For Those Who Give and Grieve is provided to all families at no cost.

Summer 2004

Visit our home for donor families at www.donorfamily.org

Volume 13, Number 1

stress and grief:

do you fight or befriend?

By Tom Golden, LCSW



Tom Golden, LCSW

I WATCHED OUR LOCAL TV NEWS THE OTHER DAY and was saddened by a brief clip about a seven-year-old boy who had been hit by a car and killed. The tragedy happened near the boy's home.

The news cameras focused on the bereaved mother as she sat in her living room in tears and surrounded by other women who tried to console her. The next image was of the bereaved father, pacing alone on the roadside near where the accident occurred. The news anchor explained that the father was trying to understand how this tragedy could have taken place.

This is not the first time I have seen this scenario. After a major loss, women often move towards a nurturing and intimate connection while men move toward “doing” something. Why are these such common scenarios? Why would the women gather and nurture one another while the men engage in some sort of activity?

Researcher and UCLA psychologist Shelley E. Taylor may help us understand these questions. Dr. Taylor made the important observation that much of the previous research done on stress was

conducted on male subjects. In the past, women had been omitted from the studies due to researchers' fears that their monthly hormonal cycles could skew the results. This original research found that, when stressed, the subjects were likely to do one of

This difference in seeking social support during stressful periods is the principal way men and women differ in their response to stress, and one of the most basic differences in men's and women's behavior.

two things: either stand and fight or retreat. This became a well-known and publicly accepted syndrome called the “fight or flight” response. Dr. Taylor has helped us see that this “fight or flight” syndrome we have heard so much about is true for men, but may not be true for women. Dr. Taylor conducted the same research on women and she found that women, when stressed, do something entirely different rather than resort to fight or flight—they “tend and befriend.” She means that, under

stress, women will move to nurture those around them (tend) or will make social connections with those they feel safe (befriend).

“This difference in seeking social support during stressful periods is the principal way men and women differ in their response to stress, and one of the most basic differences in men's and women's behavior,” Taylor asserts.

Dr. Taylor explains that there is a physiological component in these findings, which seems to be centered around a hormone called oxytocin.

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from the editor

dear friends,

IT WAS ABOUT TWO YEARS AFTER TONY DIED that I met my friend Jill. I had started a new job and as I met people, I found myself fielding all those questions I dreaded, like “Are you married?” and “Do you have children?” Awkwardly, I explained to someone that I was married...I am now a widow... my husband was an organ donor. She looked at me and said, “You need to meet Jill. Her son received a transplant.”



Rose
D'Acquisto

JILL'S SON BRENDAN WAS BORN on December 28, 1994 with Biliary Atresia, a rare birth defect where the liver has few or no bile ducts. There is no cure. By age two, Brendan would have been dead had he not received his liver transplant. Thanks to a generous family, at almost one year of age to the date, he received a second chance to live. Today, Brendan's health is excellent. Other than taking three medications a day and occasional blood draws, he is a happy, healthy nine year old—all made possible because of organ donation.



OVER THE PAST NINE YEARS, Jill has written numerous times to her donor family and has never heard from them. I've written to my husband's recipients and have heard little from them. So Jill and I have adopted each other. I listen to Jill proudly tell me about Brendan's swimming lessons. And I feel proud too, knowing I made the right decision.

AT THE U.S. TRANSPLANT GAMES, we as donor families have the opportunity to see firsthand the impact that our decision has made in people's lives. Whether or not Tony's recipient is an athlete, or somebody's grandfather, in my heart I know they are grateful more than words can express. So, when I meet a transplant recipient, I quietly adopt them—on behalf of a donor family like me. And I say a prayer for a special loved one who will always be remembered.

Sincerely,
Rose D'Acquisto
Donor Wife and Volunteer Editor
For Those Who Give and Grieve

FOR THOSE WHO GIVE AND GRIEVE

For Those Who Give and Grieve is published quarterly by the National Donor Family Council of the National Kidney Foundation (NKF). Opinions expressed in this newsletter do not necessarily represent the position of the National Kidney Foundation. The NKF reserves the right to edit all submissions. Please contact the NKF for article submission guidelines or permission to reprint articles.

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stress and grief...

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"Oxytocin has been studied largely for its role in childbirth, but it is also secreted in both men and women as a response to stress," she says. "Animals and people with high levels of oxytocin are calmer, more relaxed, more social and less anxious. In several animal species, oxytocin leads to maternal behavior and to affiliation."

Oxytocin, sometimes called the "cuddle" hormone, has been found to be a "major facilitator of maternal behavior." Researchers are finding that a woman's estrogen level amplifies the effectiveness of oxytocin, while a man's testosterone level hampers and limits the action of this "cuddle" hormone. This dramatically increases the difference in men and women following stressful situations, as men lean toward fight or flight and women toward tend and befriend. We are just beginning to discover that there are physical reasons why men and women react differently to stress and grief; oxytocin is a major component in facilitating these differences.

Is it nature or nurture? Of course it is both. Men and women receive very different messages from our culture about how to act following a loss. Importantly, we are beginning to find that there are also significant physical differences.



This is an important finding on its own, but it is especially important to help us understand the ways we choose to grieve following a painful loss. Dr. Taylor's research helps us see that women tend to seek out social contacts following a loss and find solace in being "tended." Men, on the other hand, find themselves in the midst of fight or flight, which moves them toward a stance of either running or fighting. "Fighting" will move men into a sphere where they take some action that helps them with the grief. "Flight," or withdrawal for a period of time, is

common for men and women. "Pulling back into the cave" is a common phrase that captures this potentially healthy maneuver.

Not all men rely solely on fight and flight and not all women rely solely on tend and befriend. We are all a mixture of both. Each of us, at some point, will use both strategies. The point here is that, more often, men will seek out an active mode to help them with their loss and women will seek out an interactive mode. Some women, however, may choose action oriented paths and some men will prefer the tend and befriend responses.

When we talk about these differences, we must keep in mind that we can't lump all men in one pile and all women in another. We are all unique in our path to deal with grief. 🌸

Tom Golden, LCSW is a psychotherapist, international speaker and the author of "Swallowed by a Snake: The Gift of the Masculine Side of Healing." He has been working in the field of death and dying for over 20 years.

*we fondly
remember*



Bruce K. Smith, Sr.



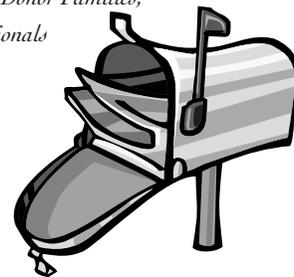
Phillip Driggers

communicating with recipients

how to write to a transplant recipient

Excerpt from the *National Communication Guidelines: Regarding Communication Among Donor Families, Transplant Candidates/Recipients, Non-Directed Living Donors and Health Care Professionals*

THE DECISION TO WRITE TO A TRANSPLANT RECIPIENT is a personal one. As a family member of a donor, you may or may not decide to write to the transplant recipients. It is completely up to you and you should feel no pressure to write.



You should also know that there is no time limit for sending a letter—you may write at any time. If it would make you feel more comfortable, you may choose to send a card during the holidays or even a “Thinking of You” card instead of a letter.

If you decide to write, here are some suggestions:

- * Write information you feel comfortable sharing about yourself, your loved one and other family members. This may include occupation, hobbies, interests or perhaps special things your loved one liked to do or information about your family.
- * You may want to write about how making the decision to donate has impacted you, your family and your community.
- * Initially, you may want to include only the first names of yourself, your loved one and other family members, as well as the state in which you reside.
- * We recommend that you keep identities anonymous and confidential. Avoid any last names, street addresses, city names, phone numbers or names of hospitals or physicians.

Sample phrases and sentences:

Here are some sample phrases to give you some ideas about

what you could include in your letter (courtesy of the New York Organ Donor Network):

- * Once again I find myself writing to you. I do not want to intrude in your life, but I can't help wondering about you. I would appreciate it if you would write and tell me about yourself.
- * I am so happy to hear that your health is good and that your body has accepted my mother's kidney. It helps us a lot.
- * I think of my daughter's recipients often. Please write and let us know how you are doing.
- * You received my precious daughter's organ and we think of you and wish you good health. Please write and let us know how you are doing.
- * Dear Recipients, We would love to hear from all of you as it helps to know that some good came out of our tragedy.
- * I was so thankful when I received your letter. It is good to know that you are well. I wish you a long life.
- * I was very happy to hear from you. Just knowing that you are doing well helps me know that I made the right decision when I donated my son's organs.

After you have completed your letter or card:

- Place the letter or card in an unsealed envelope.

- Include a separate sheet of paper with your full name and the name and date of death of your loved one.
- Mail to the procurement organization that recovered the organs and/or tissue of your loved one.

With your permission, your letter or card may be reviewed to ensure confidentiality. The transplant recipient may be contacted to request permission to forward the correspondence. This process may take a few weeks or months. If the transplant recipient does not wish to receive your communication or to communicate further with you, the professional will inform you of that decision.

Some transplant recipients may send a letter or card to you in response to your letter. Other transplant recipients may choose not to write to you at this time—this is their personal decision. Many transplant recipients have said they feel overwhelmed with emotion and have difficulty expressing their gratitude in writing.

To request a copy of the National Communication Guidelines, please e-mail donorfamily@kidney.org and type Guidelines in the subject line. Don't forget to include your mailing address. 

A tribute to my dad, Michael A. Cannella

Life, it's just a word, but what it means is not.
Everyone living has a life,
And regardless of what gets in the way,
Still having life is priceless.

Having life end would be a tragedy,
But what if you could keep another human,
From having their life come to an end.

I have a dream, which cannot be achieved in a
lifetime
But only after one.

My dream is to be an organ donor,
To give my organs and parts of me,
That are no longer in use,
To save another person from dying.

To save tears, hurt family and friends,
And mostly, to save a life.

It's an accomplishment if you save someone's life,
And I want to accomplish this goal,
In my own way.

My dream is to save a life with my donated
organs,
And save that one child, son, daughter,
Mother, father, grandparent,
Friend or co-worker of yours from a loss of life,
The most precious gift of all.
I want to give the gift of life to one more person.

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PLEASE JOIN US FOR THE DONOR RECOGNITION CEREMONY

at the 2004 U.S. Transplant Games in Minneapolis-St. Paul. This memorable ceremony is a special tribute to our loved ones who donated organs and/or tissues at the time of death. It will feature a video tribute to donors, music and readings to honor donors and their families and reflections from transplant recipients whose lives were changed dramatically from the precious gift of donation.



reflections from transplant recipients whose lives were changed dramatically from the precious gift of donation. All Games participants are being encouraged to come and honor donor families. The ceremony will be held at the Cathedral of Saint Paul in St. Paul on Thursday, July 29 from 2:00 pm to 4:00 pm.

If you would like to participate in the Games or read about up-to-the-minute details of the ceremony and the Games, please visit www.transplantgames.org

Chef O's Chocolate Chip Brownies

Dear Donor Families,

As a recipient, I think of donor families and the pain you must feel. When my sister died suddenly a few years ago, comfort foods became forefront in my mind. Here is one of my favorite chocolate recipes that I would like to share with you, with the hope that a bite or taste may remind you of the gratefulness that recipients feel toward you—because of your generosity and the selflessness of you and your loved one—for giving the gift of life.

Thank you!

Chef O

(Makes 16)

5 oz. dark chocolate, chopped into small pieces
 $\frac{1}{2}$ cup sunflower oil
 $1\frac{1}{4}$ cups light brown sugar
2 eggs
1 tsp. vanilla extract
 $\frac{1}{2}$ cup self-rising flour
 $\frac{1}{4}$ cup cocoa powder
 $\frac{1}{4}$ cup walnuts or pecans, chopped
 $\frac{1}{4}$ cup milk chocolate chips



- 1) Preheat oven to 350° F. Lightly grease a shallow 8-inch square cake pan.
- 2) Melt the dark chocolate in a heatproof bowl over a saucepan of barely simmering water.
- 3) Combine the oil, sugar, eggs and vanilla in a large bowl. Stir in the melted chocolate, then beat well until evenly mixed and smooth.
- 4) Fold in flour and cocoa powder, stir thoroughly. Stir in chopped nuts and chocolate chips, pour into prepared pan and spread evenly.
- 5) Bake for 30-35 minutes or until the top is firm and crusty. Cool in the pan before cutting into squares.

Oliver Hale, or "Chef O," received his kidney 18 years ago. He is a professional chef of French and Italian cuisine in the Michigan area and a former member of the transAction Council Executive Committee.

The Quilt on Tour



Please note: This schedule is subject to change. Call the National Donor Family Council at (800) 622-9010 for the most up-to-date information.

2004

- July 24–August 1 Minneapolis, MN, 2004 U.S. Transplant Games, National Kidney Foundation, Marilyn Jones (800) 622-9010 (entire quilt)
- August 7–8 Oklahoma City, OK, *Donor Family Recognition Ceremony*, Oklahoma Organ Sharing Network, Julie Avants (405) 840-5551
- August 21 Las Vegas, NV, *Donor Family Recognition Ceremony*, Nevada Donor Network, Anne Sagel (702) 796-9600
- October 2 New Castle, WA, *2004 Donor Family Ceremony*, Northwest Lions Eye Bank, Lois Parker (800) 847-5786

The quilt is created from squares made by donor families in honor of their loved ones. It travels in sections around the country to pay tribute to loved ones and to raise awareness of organ and tissue donation. **The quilt is not displayed in its entirety, and some events may be closed to the general public. If you plan to attend one of the displays, please contact the person hosting the event.** If you are requesting a particular panel or square to be displayed at one of the above events, would like to bring the quilt to your community, or would like information on how to contribute a square, please call the National Kidney Foundation at our national toll-free number (800) 622-9010. Information about the quilt can also be viewed on our Web site at www.donorfamily.org

"[The following] is a letter that I recently wrote to a liver recipient, but a strange thing happened: I wrote the letter and then had no real need to send it."

Dear liver recipient,

YOU ARE PROBABLY WONDERING why you are receiving this letter so many years after your transplant. Please allow me to take a moment to tell you my donor story. It may make you sad and bring back memories of your recipient story. The most important aspect to remember as you read this is "I am so happy that you are alive!"

IT HAS BEEN OVER 11 YEARS since the option of donation was presented to my husband and me after we learned that our only child, a 16-year-old boy, was brain dead. I knew it was the only "good thing" happening at that time. I had no idea this "good thing" would positively affect our lives forever. I only knew the pain that comes from the death of a child.

OUR SON WAS A GOOD KID. As a toddler, he brought me a handful of "roly poly" bugs. At 16, he worked at our local grocery store, played soccer, had a girlfriend and waxed his car weekly. I cannot tell you how many times I have spoken those words in front of an audience. I did not intend to become a speaker or an advocate for organ and tissue donation, but that is the path my life has taken. I felt blessed by the care given to me in the hospital and was thankful to the ICU nurse who told me I had the option of organ and tissue donation. I wanted to let the ICU nurses know that giving me the option of donation did not bring me pain. It gave me an option at a point in time when we had run out of options.

A WEEK LATER I learned where the organs were transplanted. I also learned about you, a 65-year-old female in Pittsburgh, PA, who was near death. I must be honest: I thought I was saving another parent the grief of losing a child, so the fact that his liver went to you, at age 65, surprised me. Then I thought of my father, who was approaching your age, and his grandchildren, who would be devastated if "Pop Pop" died. I wondered if you were a grandmother.



ONE MONTH AFTER THE DONATION I received a thank you letter from one of the kidney recipients. She wrote it several days after receiving her transplant and filled it with the emotion of a family thanking another for saving a life. I was happy for the family but grief still overwhelmed me. The next year she wrote again to let me know she was doing well and asked if she could know more about her donor, my son. I checked with our local organ procurement organization to find out what I could write. I am just like every other mother who enjoys talking about her child, so I told her about Shawn.

IT WOULD TAKE A BOOK to tell you everything that I have experienced since saying "yes" to the option of donation. Our decision to donate allowed Shawn to save lives and his legacy continues. I have the unique perspective of looking back at death but also of life—not just Shawn's life, but also the lives of those he saved. It does not take away the grief, but it does bring some degree of comfort.

I HOPE THIS LETTER FINDS YOU and your family well. My intention was to share with you a little bit about your donor. Perhaps you might want to share your recipient story with me. If not, I understand. I want you to know that I made the right decision in choosing organ donation. I have had the opportunity to meet other recipients (not Shawn's) who are my dear friends and I asked them how they would feel if their donor family wrote to them. They said they would welcome the letter, so I decided I really did want to share a little bit of Shawn with you.

Your Donor's Mother,

Mary A. Carpenter

Mary Carpenter

thoughts from
a donor dad...

memories of a special vacation

AS A FAMILY, WE LIKED TO VACATION TOGETHER. Sometimes we took a ski trip in the winter, but mostly we went to Florida when our astronaut friend, Kevin Kregel, was flying the Space Shuttle. We would visit the Kennedy Space Center for the launch and landing of Kevin's shuttle and then, afterwards, visit Disney World for a few days. My son, Rick, loved the thrill rides, and I often forced myself to go on the rides with him, just to be a "tough dad."

After Rick's death, we went to Disney World in December. Even though we knew how hard Christmas was going to be, that first time without him, my daughter, Kristen, my wife Ellen and I wanted to go somewhere Rick loved. At Disney World, we all went on the Rockin' Roller Coaster, the Tower of Terror and Space Mountain—all of Rick's favorites. After every ride—in which we were all scared out of our wits—we exclaimed, "Boy, Rick would have loved that ride!"

"Carpe Diem" was Rick's motto. Seize the Day. So we did, for Rick. 🌸



From left: Rick, Ellen, Kristen and Rich Mullane with Kevin Kregel.

writing through grief

THE NDFC IS PLEASED TO OFFER a new Writing Through Grief Workshop. The workshop will feature a moderated e-mail discussion group through our Web site in which families are invited to share prompts that help them with their writing, journaling tips and ideas for capturing special memories. Mari Stradford, moderator, will share articles and links to Web sites about writing and assist those participants who would like to submit pieces to the Comfort Café, a unique forum of the NDFC Web site that brings family and friends together to share stories and remember donors and their special gifts.

The Writing Through Grief Workshop will begin early this summer. If you would like to sign up, please go to our Web site at www.donorfamily.org Go to the Sharing and Support section and click on "Writing Workshop." Once you've signed up, you'll receive an e-mail welcoming you to the group! 🌸



The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue recovery process, to provide opportunities for families to grieve and grow and to utilize the unique perspective and experiences of these families to increase organ and tissue donation.



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