

National Kidney
Foundation™

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.



Spring 2007

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

Volume 15, Number 4

GRIEF, FEAR AND DESPAIR *as gateways to spiritual transformation*

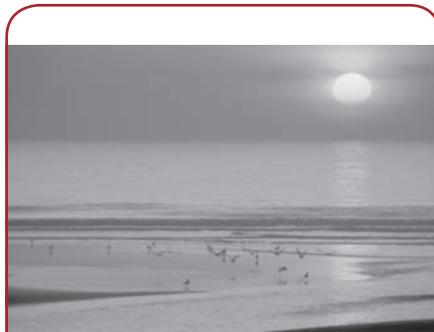
By Miriam Greenspan

TO BE ALIVE IS TO EXPERIENCE JOY AND SORROW, LOVE AND FEAR, DESPAIR AND SERENITY. The whole range of emotions is our birthright. Of course, we all prefer to experience joy, love, wonder and peace. We run away from emotions like fear, sorrow and despair. The question is not whether or not we will experience dark emotions, for assuredly, if we are human, we will. The question is: what will we do when these emotions arise?

We tend to regard painful emotions as signs of psychological fragility, mental disorder or spiritual defect. Few of us learn how to experience the dark emotions fully, in the body, with awareness.

We are accustomed to thinking of emotions as either “positive” or “negative.” But there are no negative emotions. There are only negative attitudes toward, and consequences of, emotions we can’t bear mindfully. The dark emotions have a value and purpose. They get our attention, ask for expression, transmit information and impel action. Grief tells us that we are all interconnected in the web

of life and that what connects us also breaks our hearts. Fear alerts us to protect and sustain life. Despair asks us to grieve our losses, to examine and transform the meaning of our lives, to repair our broken souls. Each of these emotions is purposeful and useful, if we know how to listen to them.



Aaron taught me that when our hearts are open, there is magic even in the midst of great pain. By listening closely to my grief, I underwent a transformational process...

I learned about the power of the dark emotions like everyone else does—through my own suffering. My first child was born and died after 66 days. Aaron taught me that when our hearts are open, there is magic even in the

midst of great pain. By listening closely to my grief, I underwent a transformational process using three basic skills: attending, befriending and surrendering to emotions that made me uncomfortable.

Attending to our emotions is about simply noticing how we actually experience them in the body; for example, through physical aches or pains, a knot in our stomachs or throats, or changes in breathing. We can practice *attending* by bringing our focus to the body and noticing where in our bodies our emotions live and how we experience them.

Befriending emotion is going one step further and extending our emotional attention spans, cultivating a greater tolerance for emotional discomfort. To practice this step, it is helpful to breathe through that location of the emotion in our bodies. The intention here is not to control or change the emotion, nor to make it go away, but rather to extend our mindfulness to the emotion through our breath.

Continued on page 2



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Grief, Fear and Despair... Continued from page 1

Surrendering is not about forcing ourselves to "let go" of emotion. It is quite the opposite: accepting the discomfort of the emotion and saying "yes" when we'd rather say "no." It is letting an emotion *be* that allows us to let go. When we are open to our hearts' pain and to our bodies' experience of it, emotions flow in the direction of greater healing, balance and harmony.

By attending, befriending and surrendering to grief, fear and despair, we discover a renewed gratitude for life.

By attending, befriending and surrendering to grief, fear and despair, we discover a renewed gratitude for life. We are released into the joy of living well with our vulnerability rather than trying to grasp at an elusive fearlessness. We discover that we can journey through the dark night of the soul and emerge with a more resilient faith in life.

Miriam Greenspan is a psychotherapist in private practice, writer and workshop presenter who lives in Boston. Her book Healing Through the Dark Emotions: The Wisdom of Grief, Fear, and Despair, won the 2004 Nautilus Book Award in psychology for "books that make a contribution to conscious living and positive social change."

WE FONDLY remember...



JAMES (JIMI) RILEY
May 20, 1984 –
January 19, 2002



CORY STUART
May 19, 1986 –
March 9, 1997



MATTHEW CUNNINGHAM
September 30, 1975 –
December 2, 2001



ROBERTO QUEBAS
October 8, 1956 –
October 18, 1994

THE FOREST FIRE *and grief*

By Rick Nickles, Donor Spouse

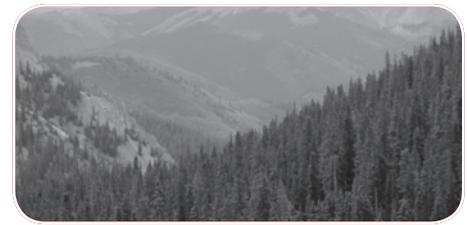
HAVE YOU EVER BEEN TO A FOREST AFTER A FOREST FIRE? THE TREES ARE BLACK AND CHARRED; it smells bad. It feels terrible to be there. The animals and birds are gone. There is an eerie silence that isn't usually there. Park rangers have told me that forest fires are nature's way of renewing the forest, as seeds don't germinate again until the fire burns everything up. I spent many years in various wilderness settings, but seeing a forest after a fire remains vivid in my memory. I have already forgotten many pretty places, but I'll never forget how I felt in that charred forest.

After a little while, if you look around, seedlings and pretty little flowers begin to show. You may see a bird here and there. Then, maybe a chipmunk or two, not many, just a few. It takes a while, but eventually the birds and animals return, just not in the same number or manner as before. The forest grows again, although it's different than it used to be.

It is often the same with those of us who are grieving. Our old life is gone and the world we once knew has been changed forever. The death of a loved one changes our own existence and may make us question whether we will ever feel good again. Moving forward is difficult, but it allows us to experience new joys.

Grief is about transition and healing. Grief is about looking for the little flowers amid the ruins.

Grief is the transition from the old life to the new life. It starts with the devastating loss and the identity crisis that follows. There are the painful voids in our lives that redirect our focus and attention so that we notice the little things we didn't notice before. Then comes living the new life, with all the growing pains that come with it. It's all about learning to walk, one foot in front of the other foot, trying not to fall. And if we fall, we get back up again and try to keep walking after the death of our



loved ones. Grief is about transition and healing. Grief is about looking for the little flowers amid the ruins.

The night I walked through the charred forest I sat on a rock and

looked at the stars and the moon. The embers were still hot and the trees crackled and burned. The moonlight was shining and I could see many varied colors dancing. The emptiness was still there, but I didn't notice it as much and I couldn't see the blackness and ugliness that remained. It was beautiful. While it was still night, I sat back and enjoyed the moonlight, the stars, the sounds of crackling and popping, and the colors dancing back and forth in front of me. I forgot about what happened for just a little while.

IF YOU'D LIKE TO SHARE A PHOTO OF YOUR LOVED ONE FOR THIS NEWSLETTER'S *We Fondly Remember* section (see opposite page), please e-mail it to donorfamily@kidney.org or mail it to:

National Donor Family Council
National Kidney Foundation
30 East 33rd Street
New York, NY 10016

Please indicate that it's for the *FTWGG* newsletter and include your contact information along with your loved one's name, date of birth and date of death.

DEATH, LOSS *and spirituality*

By Rev. Phil Pinckard, Donor Father



Mark Pinckard

When Someone Dies...

When someone we love dies, their loss may impact our spiritual life. A father tries to come to terms with the *meaning* of the death of his only son. A son tries to understand the sudden death of his mother. Recently, I counseled the family of a 48-year-old woman who died suddenly of complications from fluid in the lungs, diabetes and kidney failure. Her son said, "This is the worst thing that could happen to me. What am I going to do now?"

What Do I Do Now?

What indeed *are we* to do now? Loss tears at our identity. Who am I now that my sibling, child, parent, spouse, friend has died? Maybe our loved one became an organ or tissue donor. That may ease the pain somewhat, but the effects of his or her death lingers. Loss affects our assumptions. We assume that children will outlive parents. We assume that older people will die before young people. But parents must sometimes bury children because of an accident, an illness, a self-inflicted death or military service.

God's Face Has Never Looked the Same

In his memoir, professor and author Lewis B. Smedes wrote, "About four years into my teaching profession, [my wife] Doris gave birth to a beautiful baby boy who died before he had lived the whole of a day. God's face has never looked the same to me since. Because of my Calvinism, God's face had had the unmovable serenity of an absolute sovereign absolutely in control of absolutely

everything. Every good thing, every bad thing, every triumph, every tragedy, from the fall of every sparrow to the ascent of every rocket, everything was under God's silent, strange and secretive control. But I could not believe that God was in control of our child's dying."

Clearly for Lewis and Doris Smedes, the death of their newborn son forever altered their beliefs.

God Can Handle Your Anger

There is a fist-shaped hole in the sheetrock in our master bathroom. It was made during a weekend in August 2002 when I should have been taking my son Mark to begin training as an engineer at Grove City College in Pennsylvania. Mark died one week after his high school graduation. In a fit of anger, I made a hole in our bathroom wall.

I believe that God is able to handle our anger toward Him. It's important to understand that angry feelings are human. One major goal in the grieving process may be to "get our anger out" without harm to ourselves or others. It is okay to express our angry feelings rather than be afraid of them. Remember, you have a right to be angry! If you are angry toward God, by all means, tell Him!

Anger may be directed at the deceased: "How dare he die without saying goodbye!" "How could she do this to us?" Sudden death essentially says "I abandon you"; it is abandonment. When treated unfairly, it's common to get mad at others.

Anger must have a healthy outlet. Yelling and screaming can be healthy ways to release anger. A safe physical activity like punching pillows may be helpful. Express your rage without guilt through this difficult period.

Emerging from the Kingdom of Night

Your patterns of worship, prayer and spirituality may have changed. You may have become more spiritual. You may think more of heaven or the afterlife. Or, you may find it more difficult to worship. Your prayers may seem like they are bouncing off the ceiling.

Personally, for me, it's more difficult to go to church now than it was before my son Mark's death. I seem to be in a perennial "dark night of the soul," but I am still giving thanks through the darkness. Elie Wiesel said, "No one is as capable of gratitude as one who has emerged from the kingdom of night. We know that every moment is a moment of grace, every hour an offering; not to share them would be to betray them. Our lives no longer belong to us alone; they belong to all those who need us desperately."

As you journey on this unwanted, unexpected roller-coaster ride of grief, your trembling heart will be stilled and your life will begin to return to wholeness. You will survive! How do I know? Because if I can, you will too!

DONOR FAMILY *voices*

AFTER THE DEATH OF A LOVED ONE, THE WORLD OFTEN SEEMS A CHANGED PLACE. Some people find comfort in their spiritual or religious beliefs. Some people may find themselves questioning their beliefs or seeking new answers, and others may begin to explore their spirituality for the first time.

Did your experience with death and loss lead you to question your religious or spiritual beliefs? Is your relationship with God (or religion, spirit, spirituality) different from before? Have you become more or less spiritual or religious than you were before? Have your beliefs changed in any way?

Editor's Note: We asked families these questions on our donor family e-mail list; some of their responses follow. For those who responded, we would like to thank you for your honesty and openness. We know that this can be a sensitive and emotional subject, and the answers are different for each person. We hope that these questions and responses will help you on your own path.

To read the full responses or share your own experience, please visit www.donorfamilyforums.org

To join our donor family e-mail list, write to donorfamil@kidney.org and ask to "Join the NDFC e-mail list."

We lost our daughter Alison almost 10 years ago. God was not cut any slack in our emotions. Our relationship with God became more personal and direct. Through the spirituality of close friends, neighbors and colleagues in their practice of the Commandment, "Love thy neighbor as thyself," we found that God's love had not abandoned us.

– Pat and Will Wesley and Family

Since my wife died, I'm living in a different, less comfortable world. In my world, God moves in ways that I cannot understand and I am seeking Him in new ways.

– Douglas Harrell

My son Corey touched so many lives; he has been a huge inspiration to other teens and parents too. I don't believe God *took* my son. I know that God *welcomed* my son.

– Kelly Parker

When our 10-year-old son Ryan died, I thought my world had ended, and in many ways it had. Since Ryan's death I have been shown time and time again that there IS a God—a tangible, living, loving force. I miss my son dearly, but I know where he is and I know I will see him again. Yes, my relationship with my God is stronger...he's taking care of my son.

– Dale Doige

When I look at the tree branches swaying in the wind, I feel my daughter, Susan. When I look at the sky, it is brighter than it used to be and I know Susan is talking to me. A sunset tells me she is okay. Her oneness with nature is a great comfort, for I miss her every hour of every day.

– Bobbie Boyer

Losing my husband changed my understanding of God exponentially. I am a Christian and at that point in my life, as a 34-year-old married woman with a new baby, I thought my good fortune was a gift from God because of my good works. And then, my husband died. It was difficult to understand how something this bad could happen to someone who loved God and was living the life of a Christian. I learned that I am not exempt from tragedy because I am good. I struggle daily with the walk, but I need God more now than I ever have.

– Margaret Klavins

After my daughter Laura died, I sought confirmation of an afterlife. I firmly believe now that the earth we live on is our "school." Our "home" is in a different dimension: God's world, the world where I initially came from and will return to after I pass on. I also learned from Laura's death that I am "here" to become a loving, compassionate and spiritual individual. The world didn't change after Laura's death—I did—and for the better, I think!

– Debbie Brinkworth

Continued on page 6

DONOR FAMILY *voices* Continued from page 5

I have not been to church since my son's memorial service. I am now more spiritual and less religious. I am aware that my son is near me often. Others tell me they can sense him right next to me. I believe much more in life after death now. Maybe I should say consciousness or awareness after death.

– Tawn Head

After my daughter Amber died, I did go through the anger, disillusionment and heartfelt despair that all parents feel when losing a child. I questioned God and everything I had ever believed in. Nothing made sense and yet there is a sense of the world continuing while your whole universe and all you believe in has unraveled. We learn that there is a new world we have to face each day.

– Tammy Sneed-Lockley

My relationship with God did change. After my husband Paul died so young, so suddenly, and with so many of our hopes and dreams shattered, I have had a very difficult time turning to God. I talk to him and just tell him, *I can't speak with you right now*. Lately, I have become much more spiritual and I do believe in the afterlife.

– Grace Isrow

God was gracious to my beautiful son. He took him quickly with no pain, yet allowed him to be an organ donor, which was my saving grace in the days, weeks and months to come.

– Pam Colvell-Gleason

When my son died, my faith was badly shaken. I still believe in God and believe that he has a reason for everything that he does. I still pray and read my Bible everyday, but before, my faith was unconditional. Now I have so many questions and feel angry often. I am

trying to get back to where I was; it is hard but I will get there someday.

– Anna Parham

I never questioned my religious/spiritual beliefs prior to, or since, our daughter's parting. I have become less "religious" and now have a more simple approach, knowing I don't have to attend church or be any particular religion to be "saved."

– CindyJo Greever

After the death of my son, I became very dependent on my spirituality. I know where my son is and that is a comfort to me.

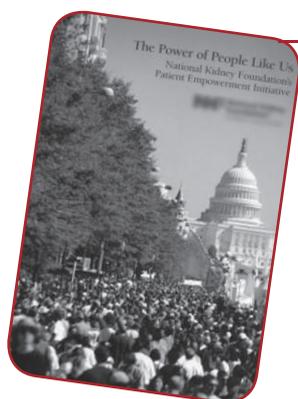
– Liz Followell

Several months after my son Johnny's death, when the shock wore off, I did find myself questioning my faith. I was angry with God, but I think I had a right to be angry. I never stopped believing in God. I just had to step away for a while.

– Karen Legieko

The death of my two children brought on a deeper understanding and love of God because of what my priest said: "God is not the puppet master pulling the strings and deciding who goes and who stays. He gives us the free will to make our choices, but He is there to pull us through whatever happens." My lifetime is just a blink in my children's eyes based on eternity. That keeps me going, along with my faith and understanding that God did not do this to me.

– Sue (Steidle) Clones



Join the NKF's New "People Like Us" Movement

STAY INFORMED ABOUT LEGISLATIVE ISSUES affecting transplant recipients, people with chronic kidney disease, living donors and donor families. Learn how you can influence public policy and the media.

TO JOIN THE "People Like Us" e-advocacy network, go to:
www.capwiz.com/kidney/mlm/signup

HEARTFELT *connections*

By Jim Gleason, Heart Recipient

I RECEIVED A HEART TRANSPLANT IN OCTOBER 1994 AND WOKE UP WITH A STRONG BEATING HEART AND A NEW LIFE. From that moment on, donor families became "real" in my life and part of my daily prayers. At the 2002 U.S. Transplant Games, I was able to meet my donor family and convey my thanks in person. I now have a photograph of Roberto, the man whose heart beats within me and makes my life possible. Not a day goes by that I am not aware of his presence.

A year ago, I married a Donor Mom who had lost her 13-year-old son. In sharing our lives, we have

both come to understand and appreciate the donor and recipient sides of this process in a very unique way. I have an even deeper appreciation of what my own donor family must have gone through in passing on their loved one's heart to save my life. I have seen what my wife went through in her own recovery from the loss of her son, and how her faith aided in that recovery. Today, we are thankful for the many gifts in our life made possible through organ donation and transplantation. Faith and prayer has made it possible to not only survive, but more importantly, to thrive in living a fulfilled life together.



Jim and Pam Gleason at their October 2005 wedding.

Now, after thirteen years with this heart transplant, I feel no physical limitations and have no emotional scars, but I do have a much stronger spiritual life. Please know that your loved ones are remembered in our prayers today and every day, along with the prayers of your own recipient and so many other transplant recipients.

"Dayenu" — Enough

By Susan Terman, Donor Wife

Here is a poem that I wrote for Passover, the Jewish holiday that took place in early April. Dayenu is Hebrew for enough, and is a song we sing as part of the Passover Seder.

My husband Bruce was a runner and ran in the NYC Marathon last year. He was hit by a car while jogging and died. As you can see in the poem, my "pet name" for him was Bruno.

I want my husband back
 Enough
 His car is in the garage
 Enough
 His clothes are in the closet
 Enough
 His running diary is waiting for its next entry
 Enough
 His graduate student Hong needs her mentor
 Enough
 His brothers need their brother
 Enough
 His twin needs the other half of his soul
 Enough
 His nieces and his nephews need their uncle
 Enough
 His books need to be read
 Enough
 His wife needs her husband
 Enough
 Come back, Bruno, come back to earth
 Heaven Can Wait.

"ATTENTION ALL YOU UNDER USED CARS!"

IF YOU'RE HANGING OUT BY THE GARAGE, JUST RUSTING, CALL KIDNEY CARS AND DONATE YOURSELF TO HELP FIGHT KIDNEY DISEASE AND SAVE LIVES."

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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. The entire quilt is not on display at these events, and not all events are open to the public. Please call the contact person for more information.

2007

- July 20–22** Washington, D.C., Division of Transplantation, U.S. Department of Health and Human Services, *National Donor Recognition Ceremony and Workshop*, Marilyn Jones, 800.622.9010
- September 8–15** Seattle, WA, SightLife, *2007 Donor Family Gathering*, Lois Parker, 206.682.8500
- September 29 and October 7** Rochester, NY, Finger Lakes Donor Recovery Network, *Donor Family Recognition Ceremony*, Roxanne Morsch, 585.272.4934

* One panel of the National Donor Family Quilt is displayed year-round at the National Donor Memorial in Richmond, VA. (This Quilt panel will sometimes be moved for display at other national events.) For more information, contact Marilyn Jones at 800.622.9010.

For information about reserving a Quilt panel, please contact the NDFC for updated information and pricing. The NDFC can be reached by e-mail at donorfamily@kidney.org or by phone toll-free at 800.622.9010. Please notify the NDFC of any special requests, including requests for a specific panel of the Quilt. Arrangements will need to be made to display the Quilt properly and obtain permission from the venue where the Quilt will be displayed.

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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