



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.

Summer 2008

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

Volume 17, Number 1

LOSING *my aunt*

By Amy Jewett, age 19



Amy Jewett with her aunt Carolyn, who was a tissue donor.

It's hard to lose someone close to you. I was in sixth grade when I lost my aunt Carolyn.

I was at a friend's house when my mom called and told me the bad news. There were so many emotions running through me, and the biggest one was disbelief. My aunt couldn't have died! I had just seen her a few days before for my birthday! And I had been so quick to say goodbye when she and my uncle dropped me off at home because I didn't want to waste their time. Now, I would never see her again.

I can't remember if I cried at her funeral or not, but I remember that my father did. I had never seen him cry before, and I don't think I've

seen him cry since. It was so surreal seeing her there. I wanted to touch her, but I was afraid that if I did I would feel how cold she was. As I went by the casket, I kept waiting for her to open her eyes and say, "It's a miracle! I'm alive!" I know this was a very silly thought, but it just wasn't like her to lay there without a smile on her face.

"My advice to anyone who has lost someone so special is to cry. Let it all out. Think about it, write about and don't be afraid to talk about it."

I had lost relatives before, but I had been smaller and they were older. They had lived long and fulfilling lives. My aunt was so young and it was so unexpected. I felt like I had wasted the time I had with her and that I should have told her how much she meant to me, so I actually ended up doing just that. I wrote letters to her, telling her how I was and how much I missed her, saying things I wished I had told her.


It helped to write my feelings down and organize them on paper. To this day, I think of my aunt constantly. She affects my life in a very big way. She had masks,

pictures and plates, all with the theme of the sun and moon together. After she died, I took this theme and made it my own to let her live on through it in my life.

My advice to anyone who has lost someone so special is to cry. Let it all out. Think about it, write about and don't be afraid to talk about it.

Don't be afraid to let your daily life distract you from it either. It is the natural healing process, to think and then to *not* think about it. Don't be afraid to let your mind wander to other things. It doesn't mean you have forgotten the person. In contrast, living your own life lets him or her live on close to your heart.

Remember in little ways. Maybe find something that was special to the person and make it special to you too. Remember the good times and make your loved one proud as you live your life.



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WE FONDLY *remember...*



Michelle Lee Bailey
August 18, 1984 –
December 24, 2004



Bernard David Boney
February 23, 1961 –
April 16, 1997



Cesar Daniel Cardoso
April 18, 2005 –
February 20, 2007



David Duane Cason
February 12, 1968 –
September 10, 1998



Sergio Rene Castellano
December 7, 1982 –
April 4, 2007



Phillip J. Frank
March 11, 1976 –
May 3, 2007



bbb.org/charity

AURORA'S story

When she was seven months old, Aurora got a scratch on her iris. We took her to the local clinic. They gave her a mild antibiotic ointment and told us to come back in the morning. Aurora also had a fever with no other symptoms. Neither the nurse nor the doctor thought the fever was related, but by morning her entire eye was being attacked by antibiotic-resistant bacteria. Three hours later, Aurora was in surgery to stop the infection and save her eye.

Aurora has now had a cornea transplant to prevent her iris from leaking through an ulcer. The transplant saved her from losing her eye. She will have the stitches removed, and once all is strong she'll have another transplant to



Aurora (left) and her twin sister at 9 months.

clear up her eye and restore her vision.

If people did not donate their corneas and we did not have this technology, Aurora would have lost her eye. Now her vision has increased and with glasses she might eventually be able to have 20/20 vision. We live in a very remote area, not close to medical facilities. If we had been further away, she may have lost her life. Having a prosthetic eye would have been hard on her and the whole family.

As soon as she had the transplant, Aurora began communicating more with her twin sister, who was feeling a lot of stress. Now three years old, they are both happier and more playful, and Aurora's medication and maintenance are minimal. I cannot thank SightLife, the eye bank, the donor and the donor family enough for what they've given my daughter and what they will continue to give. Aurora will not have the social issues other children have experienced with losing an eye. She can now have a normal life like any other child.

Thank you.
— Aurora's Parents

WE FONDLY remember...



*Rolando "Roly" Guartuche
April 7, 1995 – September 26, 1997*



*Cheryl Ann Haas
October 6, 1964 – January 28, 2006*



*Robert (RUB) Hall
July 30, 1972 – December 14, 2001*



*Joseph H. Lynch
July 12, 1937 – September 7, 2003*



*Karla Marie Parker
January 31, 1972 –
September 2, 2001*



*Barry Taylor (left)
April 4, 1966 – July 27, 2006
and
Pete Dardani
1934 – July 31, 2006*

ANGER AS A *grief reaction*

By Suzy Ball, RN, MHS Chair,
National Donor Family Council (NDFC) Executive Committee

Anger is a powerful emotion. Although everyone experiences anger, it is an emotion that is not considered to be acceptable by society. Anger during grief can be misperceived by many, especially those of us who experience it. For donor families, feelings of anger can sometimes seem at odds with feelings of grief. We're supposed to be sad, not mad! Recognizing anger, acknowledging it and understanding it will help with healing. "Everyone gets angry," states Karen Hannahs, MSW, Family Services Coordinator for Intermountain Donor Services in Salt Lake City. "After a death, at some point, anger will surface. It's a natural reaction to loss."

Why do we get angry? Someone has been taken from us without our permission, and the hole in our lives is enormous. We want to blame, to strike back at the unfairness of this event.

What makes us angry? Anyone or anything, it seems. We can get angry at our loved one for leaving us, for not taking care of themselves or for being in the wrong place at the wrong time. Often, we are angry at ourselves. We wonder if we could have somehow intervened or prevented the death. We can be angry with the health care providers, no matter how hard they tried. We may become angry at funeral directors, well-meaning friends, people who do—or don't

do—something to help us, people who say—or don't say—something to comfort us. The list goes on. Maybe the photo in the obituary is fuzzy. Maybe the weather is bad. Maybe the line in the grocery store is too long. Maybe the lawmakers didn't care enough to have that stop sign installed. Maybe the criminal or civil trial is months away. Or maybe God isn't listening.

When does anger come? Anger is sneaky and unpredictable. Our day may be going well when suddenly we hear a song that brings back a memory of our loved one. Wham! We are outraged at the injustice of our loss. Anger can happen in degrees, from feeling anxiety to irritation to full-blown rage. It can come when we feel frustrated, powerless and overwhelmed. It can come when we see others being happy, their lives still intact and unaffected by grief.

How do we feel when we are angry? The physical signs of anger include headaches, clenched jaws, tight muscles, exhaustion, poor appetite, increased blood pressure and irregular heartbeats.

What can we do when we feel angry? First of all, acknowledge anger as a normal part of grief. Anger may not make sense or seem to have a focus. It can act as a protective shield, to keep us from examining the reality of a situation or the reality of our loss. Trying to ignore it or hoping

it will go away can make you feel worse. Other suggestions:

- Pound something! A pillow, a punching bag, a nail into some wood, some dough to make bread.
- Get quiet and think: What am I angry about? What want or need is not being met? What can I do to get what I need?
- Write: Keep an Anger Log, make journal entries, write a letter to God. Try writing an imaginary letter from Dear Abby, giving yourself advice on dealing with your anger.
- Talk, of course. A spouse, trusted friend, counselor or religious leader can be a great sounding board, as well as a compassionate listener.

Is there anything positive about anger? When we recognize it and face it, anger provides us with energy to move forward. It also gives us a way of regaining a sense of control in our lives as we work through our grief. It can be productive in moving us from complacency into action.

We are unique individuals with unique loss experiences. Anger is a normal emotion during our grief journey. As we learn to recognize and acknowledge our anger, and, in turn, deal with it in positive ways, we make room for healing and hope.

DONOR FAMILY *voices* *Anger and Grief*

WHAT ARE CONSTRUCTIVE WAYS YOU HAVE LEARNED TO DEAL WITH YOUR ANGER? How have you dealt with the anger shown by those close to you? (Although it is their anger, it can also ripple into your own life.)

Editor's Note: We asked families these questions on our donor family e-mail list; some of their responses follow. Please visit www.donorfamilyforums.org to read the full responses or to share your own experience. To join the e-mail list, write to donorfamily@kidney.org and ask to "Join the NDFC e-mail list."

Anger shields you from the pain of your grief. It helps you get through the pain. The anger eventually does fade, turns to sadness, and then the sun comes out again. If after losing my 22-year-old daughter I can once again see the joy in life, I'm hoping that others in similar circumstances can also feel some joy.

— Betty Young



I was angry and took it out on everyone around me. All my energy was focused on my anger, sadness and depression. After a while, I realized that I couldn't change what happened. I had to forgive. I decided to use that energy to volunteer, do public speaking, talk to high school kids about organ and tissue donation and start a support group for donor families. I started working with our OPO (organ procurement organization). It has been 11 years and I know my son Robby would be proud of me.

— Michelle Lester



Anger is powerful and can be all consuming if I allow my mind to go there. My husband died of a brain aneurysm—no warning, no goodbye, just a life ending suddenly. Peace to each and every person walking this path. I know your pain, I feel your loss, I grieve with you and I too express anger when it is hard for me to get to a positive place.

— Karen Strickland



Our 17-year-old daughter died from an accident caused by a man who sped through a red light. We directed the energy of our anger into working to change the road on which she was killed, as well as working with the nonprofit organization that educates about running red lights. This is balanced by our work in raising awareness about organ, tissue and research donation.

— Sue Wintz

When I am really angry, the most helpful thing I can do is to exercise very strenuously—rollerblade, canoe, bike, ski or something else that burns up a lot of calories and lets me focus on breathing. This helps to restore a general sense of well-being. When I am angry or upset, really pushing my body helps me to settle down and prepare to deal emotionally with the intense situation. Then I am ready to cry, pray or do whatever else needs to be done.

— Bev Kirk



Anger is part of grieving. Accepting it is the beginning of walking through it. Anger that's not felt or dealt with can cause such pain. After losing my daughter, I had to learn to forgive those who were involved in her death, including God. I was most angry at Him. Through prayer and understanding God's heart, I was able to finally feel the forgiveness and freedom that came along with the feeling. It was NOT easy or simple, and it took years to truly feel that I had forgiven. However, it began with the desire and need to let go of the anger.

— Daphne Mayer



When I felt angry, I reflected on a poem someone gave me at my son's funeral. "When you are lonely, and sick of heart, go to the friends we know...bury your sorrows in doing good deeds...miss me, but let me go..." It helped to let a mother with young children go ahead of me at the supermarket or buy a person at Dunkin Donuts a cup of coffee. That turned a dark place in my heart into a much lighter place because I did those things in honor of my son.

— Lauren

HEALING THROUGH LOSS

can grief counseling help you?

By Dr. Robert L. Arnold, EdD, MA, BCPC, CACP, CT

A DAPTING TO THE DEATH OF A LOVED ONE IS NEVER EASY.

Although such a loss may be overwhelming, it rarely occurs in isolation. We live complex lives and death compounds that complexity. For donor families, complexity is often built into the situation. More often than not, the death:

- Occurs suddenly and is unexpected
- Happens to someone typically younger and in overall good health
- Places family members in situations that require difficult decisions.

Sudden and unexpected loss may leave you to struggle with unfinished business or with dreams unfulfilled. You also have to adapt to the reality of having a “new normal” of living with the absence of someone you love.

When our loss is complex, we may benefit from the assistance of professionals with training and experience in grief counseling. Well-trained grief counselors will honor the complexity of your life, and consider the influence of your loss on your physical health, emotional well-being and social and family relationships. They will also consider issues of spirituality and faith, and help you gauge your capacity to engage in activities of daily living.

Here are some statements that may assist you in deciding to seek grief counseling:

- Since my loss, my thoughts and emotions interfere with my work or other important areas of my life.
- Since my loss, I have an overwhelming sense of guilt.
- Since my loss, my appetite and/or weight have changed.
- Since my loss, my sleep patterns have changed.
- Since my loss, I have been having disturbing dreams.
- Since my loss, an upsetting image(s) keeps coming to mind.
- Since my loss, I am unusually irritable or angry.
- Since my loss, I feel strangely detached from others and/or my surroundings.
- Since my loss, I am using alcohol to cope with things.
- Since my loss, I am using drugs (including prescription) to cope.
- Since my loss, I have developed a pessimistic, fatalistic attitude regarding the future.
- Since my loss, I have had problems with or am concerned about my physical health.

○ Since my loss, I have thought about harming myself.

○ Someone I cared about died suddenly or unexpectedly.

If you find any one of the previous statements to be true, you may benefit from grief counseling.

Grief counseling may be provided in many formats with different degrees of intensity to meet your individual needs. Services may include: one-on-one counseling, family counseling, group counseling, peer support groups and specialized retreats.

Your local hospice is a great place to find resources to assist you and your family to begin a healing journey. Many hospice programs offer community bereavement resources of various types for all grieving persons, regardless of whether your family has used hospice services. All hospice programs will know good local referral sources. To find a hospice in your community you may go to www.nhpco.org and go to the link “look for providers.” For on-the-spot information go to www.thehospice.org and click on “Are you grieving?” There you will find information, resources and downloadable documents on grief and healing.

Editor’s Note: Dr. Arnold works at The Center for Learning at The Hospice of the Florida Suncoast, www.thehospice.org

SEEKING GRIEF SUPPORT

or other services

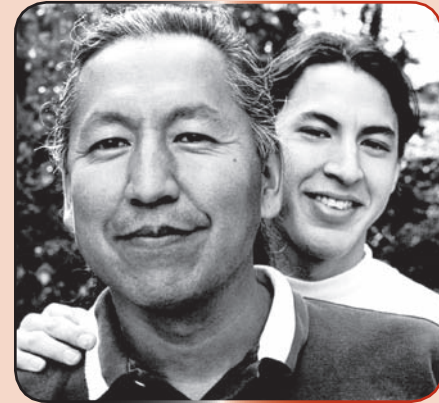
IF YOU THINK YOU MIGHT BENEFIT FROM ADDITIONAL grief support, counseling or other resources, there are many different ways to find assistance. In addition to hospice programs, which may offer counseling or referrals, you can try:

- Organ, tissue and eye recovery organizations (many offer grief support or can refer you to other resources). Contact the “Donor Family Services” department of the organization that worked with you at the time of your loved one's donation.
- Hospitals (check with the pastoral care and/or social services department)
- Funeral homes may offer aftercare services or referrals to counseling or therapy.
- School and university counseling centers
- Members of the clergy. Spiritual leaders in most faith traditions offer some degree of pastoral care and bereavement support for members of their community. In the Christian

tradition, many congregations throughout the country have Stephen Ministry programs in which trained congregational caregivers provide companionship support for the bereaved.

- Crisis hotlines (check the Internet or yellow pages for listings)
- Recommendations from family, friends or members of the clergy
- Clinical psychologists, social workers or other therapists with grief-related experience and expertise
- National organizations that offer resources for particular types of grief and loss, such as The Compassionate Friends (for families grieving the death of a child of any age), Unite Inc. (for parents grieving miscarriage, stillbirth and infant death), Sibling Grief and Healing, The Dougy Center (for children, teens and young adults who are grieving).

The National Donor Family Council (NDFC) Web site www.donorfamily.org



includes a list of more than 40 organizations that assist families (click on “Information and Resources,” then “Links”).

There are many different types of resources available, so you might need to try several different organizations to find something that fits your needs.

The NDFC also has many free print resources for donor families, along with special events, the National Donor Family Quilt and a Web site (www.donorfamily.org) where families can connect with each other for support. E-mail donorfamily@kidney.org or call 800.622.9010 to ask for the “donor family catalog of resources” or check the Web site to talk with other families.

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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.

2008

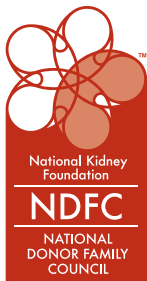
September 21 and October 5 Rochester, NY, Finger Lakes Donor Recovery Network, *Donor Family Celebration*, Roxanne Morsch, 585.272.4934

October 10 Houston, TX, The Living Bank, *Texas Stars for Life*, Lori Roy, 713.961.9431

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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