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 2006 Visit our home for donor families at **www.donorfamily.org** **Volume 15, Number 1**

SHOULD YOU SLAY THE DRAGON OR BEFRIEND HER?

from coping and surviving to transformation and thriving

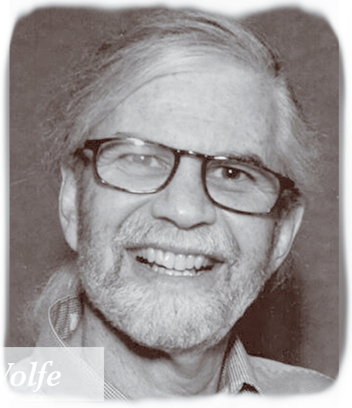
By Ben Wolfe, Program Manager/Grief Counselor
St. Mary's Medical Center's Grief Support Center

DRAGONS HAVE LONG FASCINATED HUMANS. Some adventures point to the dragon as being the villain, ravaging cities and devouring innocents. Others make the dragon out to be the hero, saving the lives of many from some other terrible beast. Where do dragons fit into the grief process? Our grief can be like a mean and nasty dragon, an unwanted, destructive force that we would rather not have to deal with if given a choice.

We know every death is "complicated," yet some deaths—especially those that are traumatic, like those often experienced by donor families—present significant challenges for survivors. Is there such a thing as "normal" grief after a death, and how does one move from coping or just surviving to transformation and thriving? Coping can and does help in reconstructing one's life, but transformation and thriving allow us to live life fully and transform our loss to evolve into creative life experiences.

Transformation is not something we do early in our grief, nor is it something for which there is a prescription. It is personal, and even in the company of others, it can leave us feeling very alone. Carol Crandal wrote, "It is not through time that one heals, but rather, what we do with the time." Being active in the grief process, rather than passive, can assist in healing. An example of being active in the grief process is the act of putting oneself on the mailing list to receive this newsletter—and/or reading parts of it. Another example would be picking up the phone and calling a friend to talk.

The Lou Holtz quote "Ten percent of life is what happens to us, ninety percent is how we respond" is a phrase that resonates with me. How do we move from trying to slay the dragon to befriending her—from trying to avoid our grief to living and thriving despite it? We know at various times in our lives, no matter how well we feel we are coping with our loss, the dragon can still "get off its leash" for moments, hours or days. In such times, we feel out of control. Although we never slay the dragon, we can learn to live with her.


Ben Wolfe

Transformation of loss is about finding our way. It is not only an individual process, but also a family process. As we move from surviving to thriving, we need to "get lost." We need to explore ourselves, not from the outside, but from within. We need to take chances, and allow ourselves to think through some of the difficult emotions that may surface, such as anger or helplessness. These may be thoughts and feelings we usually do not explore. We can remember how we survived other losses and think about the people, places or things in our history that both helped and hurt. Reflecting and remembering may help us heal. "Getting lost" is a way to stop and question the very basis of our life.

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Should You Tame the Dragon…

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Three questions help us move from just coping and surviving to transforming and thriving. The first question is: "What have I lost?" The second is: "What is left?" And finally, "What is possible?" The answers are not easy, but they move us to a new beginning filled with hope, meaning and purpose. "Moving on" does not mean forgetting or "letting go." It means we live a new life without our loved one but revisit the past periodically as we move forward. Our previous normal lives no longer exist. Therefore, we need to create new routines, new habits and new ways of doing things. In time, this new life will become normal for us. It will be a "new normal." We do this regularly, moving back and forth between the new normal and the world we once knew.

After a death, we are on a journey, with all its detours and surprises. Early on in our grief we just try to survive. We wonder if we will ever "get over" our grief. We hope to slay the dragon as soon as we can. As we become more active and less passive in our grief, we know we will never get over our grief, but rather, we allow it to transform us. We learn it really is about befriending the dragon and not slaying her. Over time, we reconstruct a new self and a new normal. We live life differently than before—knowing we will never again be who we were, but rather, we integrate the loss into our lives and create a world of hope and new beginnings.

What have I lost? What is left? What is possible?

HELPING ADOLESCENTS *cope with grief:*

The Difference Between Surviving and Thriving Following Family Loss

By Rebekah A. Arsenault, LifeLink Foundation

> *Grief knits two hearts in closer bonds than happiness ever can; common sufferings are far stronger links than common joys.*
>
> -Alphonse de Lamartine

PARENTING A TEENAGER MEANS EXERCISING SKILLFUL CONTROL: you need to know when to provide motivation, foster independence and sometimes straddle the line between the two. But helping a teenager struggling with the loss of a loved one does not have to create more conflict in the family.

Griefworks, a bereavement support network in British Columbia, states that most teens turn to friends or peers for support after losing a parent, sibling or other family member or friend. “The experience of grief increases a teen’s sense of isolation,” note these experts. “In the process of examining the values and beliefs they learned as children, and then defining their own values and beliefs,” teens “are torn between wanting to be independent and needing support from their parents and family” when someone dies.

But for a family, the difference between *surviving* and *thriving* sometimes lies in the support everyone provides one another. A hospice theorist recommends that parents remember “teenagers do not choose between grieving and not grieving; adults, on the other hand, have a choice—to help or not to help teens cope with grief.” Although each family is different, some coping methods have proven more successful than others:

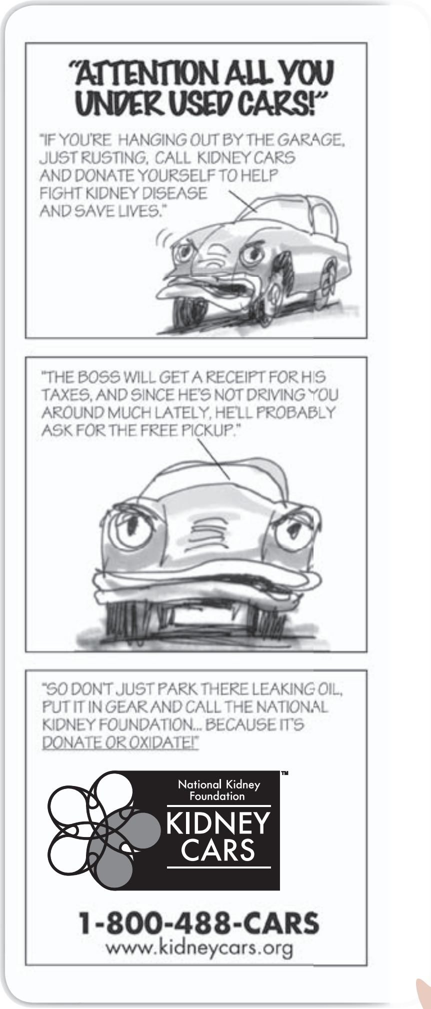
Do not force your teen to talk. You can spend time together reflecting on your feelings without speaking.

- Share the normal grieving process. Teens grapple with feelings of inadequacy on a daily basis. Let them know that a variety of feelings—including anger, guilt, frustration and anxiety—are normal and to be expected.

- Do not force your teen to talk. You can spend time together reflecting on your feelings without speaking. Watch a sad movie, listen to songs, or look at photographs or artwork that can reflect deep emotions. Although these tools can promote conversation, accept that they are worthwhile and helpful even if they do not.

- Practice active listening. Remember how difficult it was to get your teen talking about far less significant things than their deepest pain or fear. Understand that your teen might not want to talk at times you would expect, and whenever they are ready to communicate, make listening a priority.

Because teens value their independence and often give the impression they have everything under control, parents may be quick to believe everyone is coping well. Using these strategies can help ensure that the family works through their difficult emotions together.



Thoughts From Donor Families

I Miss You ~ In Memory of Toni S. Copley

By Evie and Bobby Copley, Donor Parents

In the evening of 1980
God gave to me
A beautiful little girl,
and I was a mother to be.

She was so tiny and fragile
Lying there,
And I knew I would love her
And give her care.

I cherished her and we
were the best of friends.
Her hair was dark
and her skin looked like tan.

We played together
and had lots of long walks.
In a blink of an eye
she grew to be a beautiful,
caring young woman.

And now I grieve for her
and all of our little talks.

I never dreamt that God
would take her so soon.
But I guess God knows when
his roses are in bloom.

I know in my heart
that her love for me
will always go on.


Toni S. Copley

For our life we had together
will never really be gone.

With all the good memories
I hold dear in my heart
I know that God wouldn't
dream of keeping us apart.

So Toni and I know that
in order to feel and touch
I can look up to heaven,
where I know you are.
In my eyes I know
God gave me the brightest of His stars.

WHEN YOU HAVEN'T HEARD ANYTHING, *feel free to call*

By Suzy Ball, RN, MHS, Donor Wife

WAITING FOR FOLLOW-UP INFORMATION ABOUT YOUR LOVED ONE'S DONATION CAN PROVE DISAPPOINTING. When donation was originally discussed, or when you gave consent, perhaps you were asked if you would like to receive a letter or call about the outcome of the donation. If you said yes, you may have been given an approximate timeline to expect communication.

So you waited, and then waited some more. No letter or call. Now what?

Each organization has a different method of working with donor families. Some have dedicated Family Services staff members who may contact you to introduce themselves and explain how they will support you through your grief journey. Others may simply provide mailings at specific times of the year, such as before the holiday season. In some organizations, follow-up is done by staff along with their other job duties, and may not be as timely as anyone—either you or they—would like. If an organization has many donors, they may not be able to keep up with the numbers, and they may wait for you to call them. Finally, there are organizations that only provide information if the transplant was successful, even if you also consented for research or asked to be told of any outcome.

It is okay to contact the recovery organization for information. If you were given a name at the time of the donation discussion, or can recall whom you spoke with, feel free to call that person and remind them that you requested to know the outcome of your loved one's donation. That may be all that is necessary to get information, even if all outcomes are not yet known.

Because of the short window of possibility, initial cornea and organ outcomes are known within a few days of donation. Tissue donation requires an extensive quarantine and medical approval process, so you will not hear about specific distribution or recipients for at least several months. Still, you are entitled to be informed that tissue recovery took place, and how soon you can learn about those who will receive your loved one's gifts.

Ideally, you will receive timely follow-up from all organizations involved in the donation. You may also

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Thoughts From Donor Families

when you haven't heard…

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be given some information about the recipients. Some of you may even receive a letter of gratitude from a recipient, which can give you a feeling of peace about the gift of your loved one.

Some of you, however, will not learn the outcome of the donation. You may wonder what happened to the precious legacy of your loved one, and the lack of closure might leave you feeling disappointed or angry. You may feel as if the donation was not significant unless there is an identified recipient. It is important to find reassurance in knowing that the desire to give is as important as the actual gift. You belong to a special community of people who thought of helping others at a time of tremendous personal loss. You are a "donor family." Your gift was intended for an unknown recipient who was relying on your generosity in order to return to a state of health.

> *Without your decision, there would be no transplantation. There would be no hope for those who wait.*

The National Donor Family Council defines "donor families" as:

- Families with a loved one who died and donated their organs, tissues, or both
- Families who would have liked to donate, but could not because of medical or other reasons
- Families who did not donate, but might have, had they been given the opportunity.

As a donor family, you are entitled to participate in any donation-related activities in your community. Contact your local transplant organization to learn about local events such as donor recognition ceremonies. There you will meet other donor families and have the ability to share your experiences. Volunteering and becoming a donation advocate may also prove satisfying. As a donor family, you are in a unique position to offer support and a voice to increase donation awareness.

Without your decision, there would be no transplantation. There would be no hope for those who wait. All recipients are "your" recipients. In fact, the "anonymity" of your gift can be seen as a contribution to all those who wait, as well as those doing research to improve everyone's lives. It was a powerful gift, so be proud of your decision to donate.

AS A DONOR FAMILY MEMBER, you should be aware that there are resources to help you obtain information about your loved one's donation. The National Kidney Foundation offers the *National Communication Guidelines Regarding Communication Among Donor Families, Transplant Candidates/Recipients, Non-Directed Living Donors and Health Care Professionals*, which explains the process for facilitating communication among these groups. This booklet was written primarily for professionals. From this, the brochure *Writing to Transplant Recipients* was developed for donor families.

THESE PUBLICATIONS PROVIDE guidance to donor families who wish to write to their loved one's recipients. The brochure includes suggestions for writing a letter and sample phrases to help you get started. It also explains the process for sending a letter to the recipients through your local organ recovery organization.

TO REQUEST A FREE COPY of the *National Communication Guidelines* or the brochure *Writing to Transplant Recipients*, contact the National Donor Family Council by emailing **donorfamily@kidney.org** or calling 800.622.9010.

UNKIE *mark*

By Abigail Taylor, Donor Niece

Tell me a story
About days that have passed
Tell me any story as long as it lasts
Tell me a story
And help me forget
About how bad the world is
And all the tears wept.
Tell me a story,
Maybe about sunshine.
Any kind of story,
Where everything's fine.
Tell about meaning.
Tell about motorcycles.
Tell about friends.
Tell about your son.
Tell about family.
Tell about love.
Don't tell about days
That are not so good
Or about stars that no longer shine
Those things we don't want to know.
Because you are among the things that are not here.
We can do without the bad stories,
But we will not leave you behind.
Tell me a story,
Anything about heaven.
I want to hear
About the time you are having.
Please tell me now.
Let it wash the sorrow,
For I know that you think of me
When you look down from heaven.
But you are not here to tell me a story,
You are in heaven with so much more glory.
So tell me from there
A story you love the most.
I'll be here listening
To what you have to say.
Whenever you need someone talk to
I'll be here waiting for you to call on me.
This will be our story.
I love you so much Uncle Mark, and I miss you.
We all miss you.
You'll be in my heart and thoughts forever. Ride with the wind.

THE ROAD *to healing*

By Bobbie Boyer, Donor Mother

Susan Jane Perkins

ONE PERSON'S TRAGEDY BECOMES ANOTHER PERSON'S JOY. My daughter was a single mother of two sons, who was only 34 when a terrible crime ended her life. Her death was an unbelievable tragedy but became very important to three families because she had made her wishes to be an organ donor known to her sister. She gave three people another chance, and now they are living life to the fullest. What could be a greater gift? A patch of love made in her memory is on the local TransLife Florida donor memorial quilt. "Bittersweet" is my life, for I am her mother. I miss her terribly but am very proud of her. The road to healing is remembering her unselfishness.

A patch in memory of Susan is on the TransLife Donor Family Quilt.

DONOR *family voices*

IN THE SPRING 2006 ISSUE, we asked, “What are some things you have done to help along your grief journey? What has given you comfort or hope?” We hope that these suggestions will be helpful to all donor families as you travel on your path. The full responses will be published on our Web site at **www.donorfamilyforums.org**; you can also share your own ideas there.

We take our “D-Day” and spend it in whatever way helps us. It may be a few days of quiet time alone or with special friends. It may be a new decoration for the cemetery or a tree planting in our son’s name. Last year it was a celebration with the National Quilt in our own hometown! We plan what feels right for us.

–Pat J. Kupfer

* * *

I learned, very early on, to ask. Ask for five minutes of time, ask to be invited to dinner, ask to be included in whatever friends are doing today…ask to be left alone, but not for too long! …I have been lucky in my grief journey…Everything has conspired to push me along the path, to keep me moving forward, while providing me with the space to honor the past.

–Rodney Fiddaman

* * *

I have made up an album and memory box for my son’s daughter, who was a toddler when he died.

–Bonnie Jotblad

I have an area in my bedroom that is a shrine for my parents. It has their wedding picture, cards that I have given them and a chair where I sit and talk to them.

–Yvonne Kuehn

* * *

I hold on to the fact that he helped others…my son was 16 and he left me too early in life… I know he was a champion, and now he has championed for others to live.

–Donna Field

* * *

I maintain a small garden with my husband’s favorite flowers and try to walk or bike often in the park, where he and I enjoyed many happy hours.

–Laurel Schwass-Drew

* * *

Photography has become a release for me. It allows me to capture all of the beauty that surrounds us.

–Wanda Murray

Since his death…I keep busy in participating in donation and transplant-related events. I love to speak on behalf of donation and for Dennis. It gives me comfort and it keeps him close to me.

–Patti Rivetti

* * *

For the first several months, I went to the cemetery almost daily and just sat at his grave site and talked to him. I played his favorite music for him even though I knew he couldn’t really hear it. I’ve listened to his favorite CD so many times that I now actually like hip hop music.

–Rosalind Hood

* * *

I got a small puppy to help occupy my time and mind when I was tired of thinking about the loss. Keeping busy was invaluable.

–Donna Tope

* * *

I think of April 21st as the day of Casey’s donation of life to others. It was looking past his death and embracing the lives that he has saved that has eased my grief.

–Julie (Dinsmore) Myers

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.

2006

September 23	Sioux Falls, SD, Avera McKennan Transplant Institute, *Avera McKennan Transplant Fair,* Becky Jansa, 605.322.3017
September 30	Seattle, WA, Northwest Lions Eye Bank, *2006 Donor Family Gathering,* Lois Parker, 206.682.8504
September 30	Fayetteville, AR, National Kidney Foundation of Arkansas, *Walk, Run, Sprint for Life,* Ashley Meisner, 479.200.1002
October 8	Morton, IL, Musculoskeletal Transplant Foundation, *Remembering Those Who Are Changing Lives Through Tissue Donation*, Jeri Hardling, 309.370.1192
November 2	Phoenix, AZ, International Institute for the Advancement of Medicine (IIAM), *IIAM Memorial,* Marlene Kilian, 602.697.0130
November 5	Maumee, OH, Life Connection of Ohio, *Donor Recognition Service,* Lara Clemens Angel, 419.893.1618

* 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.

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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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