

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.

Winter 2004

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

Volume 12, Number 3

winter's gloom

By Darcie D. Sims, PhD, CT, CHT, GMS

Adapted with permission from the author



Darcie D. Sims

I have packed away the few holiday decorations we pulled out, and I've cried the tears that accompanied each treasured memory and piece. But now what? I want to wrap myself with good feeling things again, to hide from the winter's gloom. Yet it still creeps inside me and lingers far longer than it should.

There is often a letdown after the holidays. We're relieved that we survived the glittering season, but often we are left without a sense of direction or purpose when January sneaks up on us.

If you are in the midst of grief, January brings its own special kind of pain. It's another year without. It's another year of memories growing dimmer. It's another year of discovering that grief takes too long.

In January, I grow especially weary of false hopes, too-bright smiles, plastic sentiments and people whose New Year's resolutions seem to be to cheer me up!

Maybe I don't want to be cheered up. Maybe I want to be depressed. Maybe grayness suits my mood as well as my appearance. But maybe not, too. What I do know is that whatever my mood in January, it's

mine! And I want to keep it—at least for a little while.

Friends and family often get upset because we might be depressed. They can't stand to see us glum. It's as if our emotional state is a direct result of their actions and an insult to their intentions. There are some real reasons for my gloom—some are due to weather, some to circumstance and some are just plain human related. But it is my depression and my gloom. They are my feelings and I need to have them for a while.

Depressed people are not fun. We don't sparkle at dinner parties. We don't radiate charm and warmth. We are not the first choice for an evening's companionship, and sometimes we stare at the television for long periods of time without really seeing the program. Sometimes we cannot concentrate

and we forget where we put the car keys. Sometimes we spend hours looking through scrapbooks and use inordinate amounts of tissues. But whatever we may be, we are functioning through our situational depression. Although it looks and feels uncomfortable, a period of depression during the journey through grief is as normal and natural as the periods of anger, guilt, fear and hurt that also accompany this journey. Depression is an extremely difficult emotional state, one that is hard to define and even harder to endure.

Grieving people often become the target for loving and concerned family members and friends who simply cannot stand to see us "down." These loved ones become driven with the task of lifting us up, out of our gloom. We appreciate their kind and loving gestures of concern. Perhaps if our loved ones

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Announcements

For Minnesota's Governor



ON SEPTEMBER 25, 2003, for the first time in Minnesota history, Governor Tim Pawlenty and First Lady Mary Pawlenty participated in a Donor Recognition Ceremony hosted by LifeSource, Upper Midwest Organ Procurement Agency, Inc. In recent years, the Governors of South Dakota, Wisconsin and Iowa have participated in similar events.

The Donor Recognition Ceremony honored LifeSource donor families from all over the state as well as a number of tissue donor families. Roughly 900 people attended the event, representing approximately 250 donor families. Each family received a medallion, which was awarded personally by Governor and Mrs. Pawlenty.



At the close of the ceremony, Governor Pawlenty thanked all donor families for their generous gift of life. He confessed that, prior to coming to the event, he had not yet indicated on his driver's license that he would like to be an organ donor. He said the stories he heard from donor families made him realize, however, the necessity of making his wishes known. 🦋

Photos by Jim Mims

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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winter's gloom ...

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understood, however, that a certain amount of depression is appropriate and even necessary within the grief process, then we could all relax a bit about muddling through this mysterious emotional state.

Depression is not only part of the journey through grief, it is natural. One day, the grieving person realizes that even the pain of grief has disappeared. Where once there existed a searing pain somewhere near the heart, now there is nothing. It is as if we have fallen into a vast nothingness, a void where not only painful feelings have left us, but good memories as well. Some of us believe we have lost the sound of our loved one's voice and the visual pictures we carry with us. We are cast into an empty gloom—truly a most difficult part of grief!

I have learned, however, that this vast emptiness is quite a busy time for those of us who are struggling through grief. Though



When we tumble into the nothingness of grief, we really are busy searching for clues to the question, "Who am I now, after my loved one is gone?"

we may appear listless and may even "hibernate" or withdraw for a time, this period of situational depression serves its purpose, as do the other emotions of grief.

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When we lose the framework of our personal identification, we must search for new identities, and part of the grieving process is in this search.

When we lose the framework of our personal identification, we must search for new identities, and part of the grieving process is in this search. If we can think of this depressive period as a gathering time for this new identity, perhaps it would be easier to understand. Am I still a mother if there is no child to tuck in at night? Am I still a dad if there is no one to loan the car keys to? Am I still a husband or wife if there is no one sleeping on the other side of the bed? Am I still a sister, a brother, a friend? Who am I now that my loved one has died? This is a painful yet necessary question. During our gloom, we are busy gathering all our scattered pieces, looking for the place in the puzzle where they belong. We are gathering all the pieces and trying to

create a new picture of ourselves, a new identity, a new "me."

This re-creation of ourselves is a vital yet solitary job. No one can help us create the new identity that we must find on our own in order to continue our journey. Each of us must take the steps to seek out a new and different us—not necessarily a stronger or "better" person than we were, but definitely a different person from who we were before our loved one died.

Depression that is a part of grief can become a more serious condition if it is not acknowledged and addressed. If the depression seems to develop into a debilitating condition or lasts far longer than even the grieving person is comfortable with, or if it seems to include thoughts of self-destruction rather than self-identification, then further assistance from a professional may be required.

But first, explore your gloom and do not fear the absence of sunlight. Be patient with yourself and others, and remember that January might just be your gathering time. 

Dr. Darcie D. Sims is a bereavement and grief counselor and educator. She was the keynote speaker at the National Donor Recognition Ceremony and Workshop in Washington, DC, in July 2003. Dr. Sims is the author of numerous books and articles on grief.

what helps *when it hurts*

Once Lost, Now Almost Found

By Dianne Pallo, Donor Wife

I am neither educated in nor a trained expert on bereavement. What I am expert in is my own feelings and experiences and what helped me along in my own grief journey, which is a daily roller coaster.

This journey began when my 53-year-old husband, Michael, passed away very suddenly on February 11, 2002 from heart complications. We were married almost 31 years. We have a 30-year-old son who is recently married and lives near New York City, and a daughter, 27, who lives near Boston.

“What am I going to do now? How will I ever live without him?” kept running through my head. I was in my 50's and had never lived alone before. The following is what helped me cope.

Michael was a bone/tissue donor, which is how I was intro-

duced to the procurement organization in my area. In addition to the emotional support that I continue to receive from family and friends, I feel blessed to have another circle of “extended family”—other donor families from the procurement organization with whom I volunteer and share grief. I have felt so embraced, as if a large butterfly's wings are around me.

I declare in my title “Once Lost, Now Almost Found.” I felt lost for a very long time, but becoming involved with the procurement organization as a volunteer gave me purpose. I say I am “almost”

found because my grief journey continues—what path it will take, only God knows. Though there are still tough times to get through on that roller coaster of daily life, I can give myself a pat on the back for not giving up, even when there were times when I wanted to.

This year, for my 53rd birthday, I did something special. Many years ago, Michael bought me a filigree heart. As I admired it one day, along with Michael's wedding ring, I saw that the heart could fit inside the wedding ring. I went to our local jeweler and asked if he could combine the two and engrave into the wedding band the phrase “Forever in My Heart.” He could, and it came out beautifully.

REMEMBER: There is no right or wrong way to grieve—only my way! 

Special Thanks...

The National Donor Family Council would like to thank the following organizations for their generous donations to support the Council's programs:

- Center for Donation and Transplant, Albany Medical Center
- Association of Organ Procurement Organizations
- Donor Alliance, Inc.
- Gift of Hope Organ & Tissue Donor Network
- Kentucky Organ Donor Affiliates
- LifeChoice Donor Services
- New England Organ Bank
- Upstate New York Transplant Services, Inc.

thoughts from *donor families*

The ABC's of Being a Donor Family

By Pat Brown, Donor Mom

A is for **A**ccepting the loss of our loved one.

B is for the **B**ooks we read to help us understand the grieving process.

C is for the **C**hildren and the crying. We cry and mourn the loss of a loved one, but we should also try to comfort and not forget the grief that children experience.

D is for the **D**oor that seems to have closed the day a loved one dies, a door which must not remain closed but be helped open for the living to begin their healing.

E is for **E**ducation. What is brain death? How did our loved one die? The more we learn about the death, the more it will help us come to terms with it.

F is for the **F**oolish things people say to grieving families to comfort them.

Forgive them for their ignorance and accept on faith that they mean well.

G is for the **G**ift of life (organ donation) that was given the day our loved one died.

H is for **H**elp that we need to seek. Grief does not know time frames. It can be 10 days,

10 months or 10 years after the death, but we should seek help when we need it.

I is for the **I**nnocence that we lose when we realize that life is not fair. We no longer assume that life goes on. Rather, we learn to live today—there are no guarantees for tomorrow.

J is for the **J**ealousy that we feel when other families appear to have normal lives.

K is for that last **K**iss we gave our loved one, the kiss that showed our loved one they were loved.

L is for the **L**ove that did not die but rather lives on in our hearts.

M is for the **M**emories that we will cherish forever.

N is for the **N**urturing that we gave our loved one and that we need to continue to give to our remaining family.

O is for **O**penness that we need to have with our families and friends about what we are feeling and the support we need.

P is for the **P**resents that we will no longer be buying. Pick something special for the grave or for the home to help remember your loved one on those anniversary days.

Q is for the **Q**uestions we all ask but cannot answer.

R is for **R**est, which seems hard to obtain but which we need to get through the long days of grieving.

S is for the **S**taories that we should tell about our loved ones to keep them alive in our hearts.

T is for the **T**ime you must give yourself to grieve.

U is for the **U**nderstanding that we must have that the world will go on and that our lives will eventually be put back together.

V is for the **V**irtue of overcoming the many roadblocks that life puts up.

W is for the **W**hy's, which can drive you crazy, and the **W**isdom to know there may never be any answers.

X is for the **eX**tra strength and love it takes to be a donor family member.

You are an extra special person for your generosity.

Y is for the **Y**ou that needs to bring yourself to terms with your loss. Only you know what helps and what does not help in your grief journey.

Z is for the end, the end of the alphabet, the end of a life, but never the end of our love.

The life of our loved one ended but their organ donation allowed life to begin anew for another.



more thoughts from *donor families*

"I'm Free"

By Leah Lorene Butts, Donor Wife

In loving memory of William David Butts

Don't grieve for me, for now I'm free,
I'm following the path God laid for me.
I took his hand when I heard his call,
I turned my back and left it all.

I could not stay another day,
To laugh, to love, to work or play.
Tasks left undone must stay that way,
I found that place at the close of day.

If my parting has left a void,
Then fill it with remembered joy.

A friendship shared, a laugh, a kiss,
Ah, yes these things I will miss.

Be not burdened with times of sorrow,
I wish you the sunshine of tomorrow.
My life's been full, I savored much,
Good friends, good times, a loved one's touch.

Perhaps my time seemed all too brief,
Don't lengthen it now with undue grief.
Lift up your hearts and share with me,
God wanted me now, "He set me free." 



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

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|-------------------|--|
| April 1 - April 9 | Dallas, TX, Southwest Transplant Alliance, <i>Texas A&M Promotion</i> , Pam Silvestri (214) 522-0255 |
| April 3 - April 5 | Montgomery, AL, Alabama Organ Center, <i>Transplant Picnic</i> , Jane B. Geloneck (334) 271-1690 |
| April 17 | Las Vegas, NV, Nevada Donor Network, <i>Donor Family Recognition Ceremony</i> , Anne Sagel (702) 796-9600 |
| April 24 | Modesto, CA, California Transplant Donor Network, <i>Celebration & Remembrance 2004</i> , Trace'e L. Harris (209) 545-8400 |
| April 24 | Fullerton, CA, Gift of Life, <i>Gift of Life Run/Walk</i> , Kathleen Hostert (714) 526-0181 |
| May 12 | Rochester, NY, Finger Lakes Donor Recovery Network, <i>Donor Family Celebration</i> , Roxanne Morsch (585) 272-4934 |



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

Never Fade Away

By Jenna Doyle

When I look at pictures of you it's as if
you're still here
And then I realize I'll never get another
chance to hold you near

We'll never get another phone talk or
another night out
We'll never get into another fight so no
one can end up walking out

Never saw this happening, or even coming close
Never thought I'd lose you so fast,
but that night I lost all hope

I wish that you could come back from
wherever you are
But instead I guess you'll watch me
from your little star

So if you read this from way up there
I want you to know that I don't think this is fair

And if I could, I'd bring you back
But I have to face facts, it doesn't happen like that

So I'll wait until my time is up to come to see you
But until that time, all I can do is say

I love you sis. I miss you more every day
The time we had together will never fade away. 🌸



A Teen's Prayer: Never Lose Hope

By Erin Elizabeth Stierwalt

Help me to never lose hope.
The times may be gloomy and light is out of sight,
loneliness surrounds us
and we can't see through our tears.
Our heart is wounded
and our body aches.
With God and our own strength and willpower,
there is always hope.
When the road goes wrong
you must stay strong,
keep hope by your side and
it will be your guide! 🌸

*Erin's cousin Michael Brown died 10 years ago
and donated his heart and liver.*

donor family *friends*

DF-169— My name is Allyssa Vittitow and I'm 11 years old. My Uncle George died almost three years ago and he was a donor. I am writing to request a pen pal. I have feelings and sometimes I wonder if another person had somebody die who was a donor and how would they feel. I'd like my pen pal to be:

1. 11 or 12 years old
2. Girl or boy
3. The rest doesn't matter.

I have friends but sometimes I wonder if they are really my friends. I need somebody to talk to, someone who won't tell everything I say. If you have time, please send me a pen pal soon! 🌸

To submit a donor family friend ad or to respond to a letter, send correspondence to Donor Family Friends, The National Kidney Foundation, 30 East 33rd Street, New York, NY 10016. Please include in your letter the number of the DF to which you are responding.

2004 TRANSPLANT GAMES DONOR FAMILY LIAISON PROGRAM



For the 2004 U.S. Transplant Games, the NDFC has asked each Team Manager to appoint a donor family to serve as a liaison to the NDFC and coordinate local donor family participation in the Games. These very special volunteers will invite donor families to the Games from their area, provide information and support to donor families before and during the Games and assist Team Managers in donor family relations, among many other tasks. We invite donor families to contact us if you would like to receive more information on the donor family liaison in your area. 

COALITION ON DONATION'S ROSE PARADE FLOAT

The Coalition on Donation participated in this year's 2004 Rose Parade in San Diego, CA, on New Year's Day with a new float themed *A Symphony of Life*. The Coalition on Donation Rose Parade Float is a milestone in raising awareness of the growing need for organ and tissue donation, and the National Kidney Foundation is pleased to be an Official Partner of this important project.

The 50-foot *A Symphony of Life* float featured two gardens connected by a dramatic 50-foot bridge,

symbolizing the living bridge between organ and tissue donors and recipients.

The Float carried 22 transplant recipients, organ donors and donor family members and was float #21 out of the 50 in the parade's line up.

To learn more about the inaugural run of the Coalition on Donation's Rose Parade Float, please visit www.onelegacy.org and click on the Coalition of Donation/Rose Parade composite logo in the upper right corner. 

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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