

FOR THOSE WHO GIVE AND GRIEVE

A Book For Donor Families

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© June 2015 Twelfth Edition

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ISBN: 0-9629721-3-4

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Dedication

In loving memory of Katie, who lived, laughed and loved, and who helped us know what to do. We don't know who the direct recipients of her gifts were, but we do know that many people have benefited from them.

And to all organ and tissue donors—may their families find peace, love and hope.

We fondly remember...



Katie Coolican

August 16, 1977–September 25, 1983

*Her memory continues to help and guide us
in our work with donor families.*

*Our love to the entire Coolican family.
– National Kidney Foundation*

***“What we call the beginning
is often the end. To make an
end is to make a beginning.
The end is where we start from.”***

from “Little Gidding” by T. S. Eliot

Grief is different for each of us. If you aren't ready to read this book now, please put it aside. You may be able to turn to it at a later time.

If you have questions or concerns about your loved one's donation, we encourage you to contact the organization below or the NKF's National Donor Family Council. We have resources that may help you.

For More Information

Contact: _____

Address: _____

Phone: _____

Email: _____

Notes: _____

If no organization is listed above, please contact:

National Kidney Foundation

National Donor Family Council

30 East 33rd Street

New York, NY 10016

Phone: 800.622.9010 or 212.889.2210

Visit us online at www.kidney.org/donorfamily

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Table of Contents

A Letter from a Donor Mom	vii
Preface	ix
Introduction	1
Who Are Donors and Their Families?	2
If Your Loved One Was an Organ and/or Tissue Donor	3
Donation after Cardiac Death	3
Understanding Brain Death	3
If Your Loved One Donated to Research	4
If You Receive a Bill by Mistake	5
Do Transplants Really Work?	5
When Our Loved Ones Died... Thoughts from Donor Families	7
Grief Is a Natural Response to Loss	9
Guilty, Sad and Lonely	9
Exhausted and Depressed	10
Am I Losing My Mind?	11
Anger as a Grief Reaction	13
Grief and Spirituality	15
What Can Help?	19
Coping with Sleep Difficulties While Grieving	22
Nutrition: The Foundation of Self-Care	27
One Step at a Time	30

Renewed Grief	31
How a Memorial Space Can Help a Grieving Person	33
Ask for What You Need	35
A Husband's Letter to His Friends and Coworkers	36
Healing through Loss: Can Grief Counseling Help You?	38
Seeking Grief Support or Other Services?	40
Getting the Support You Need	41
Grieving Children, Children Grieving	43
Helping Adolescents Cope with Grief	45
Going Home after Donor Events	47
What to Do with Our Memories	49
As Time Goes On	51
Transplant Recipients	53
Writing to Recipients	53
Thoughts from Transplant Recipients	55
Donated Skin Saves Burn Victim	56
Aurora's Story	57
Forever Linked	58
The Smile that Love Restored	60
About the National Donor Family Council	62
Online Home for Donor Families	63
Suggested Reading	63
Bereavement Resources and Support Groups	64
Our Heartfelt Thanks	65

A Letter from a Donor Mom

As a donor family member, I have some understanding of how you may feel. Know you are not alone. Your pain is shared by those of us who have also learned to live without someone we love.

Tragedy strikes when we least expect it, and we never expect it to happen to us. How could I have guessed on a bright, beautiful fall day in 1983, as I watched my healthy six year old skip down the driveway to board her school bus, that it would be for the last time?

She turned, waved and gave me a big dimpled smile; the last I was to see. Six hours later, she collapsed on her school playground from a sudden brain hemorrhage, and within a few days, she became our family's first organ and tissue donor.

I thought my world had ended. How could this have happened? How could I go on? It wasn't real. Children don't die, and certainly not my child who was so full of life and love which she gave so freely. No one could really understand how I was feeling. I felt alone. The pain was unbearable. I thought I would never laugh again.

As the months passed, I slowly came to understand that death does happen. Death is an inevitable part of life, an ending, but also a beginning. Slowly, very slowly, with the love and support of my family, some old friends, and some new ones too, I have gone on. In the beginning, I took small steps toward healing, just one minute at a time. Then slowly, I found that I could handle a whole day. At times, I was hard on myself. I should feel better. I should be able to do this or that. There was guilt and anger, sadness and loneliness. There must have been something I could have done to save my child, but there were no answers.

And then, I began to realize that I could once again appreciate a blue sky, a pretty flower or a child's giggle. The days did go on; the pain was softer. I didn't feel so alone, and I could laugh again. The love that Katie and I shared will always be with me. I came to understand that never having had her love, never having had our Kate, would have been the greatest loss of all. She lived, she gave to others, she made a difference.

And so, I say to you now, you need not be alone, your pain may soften in time and you may laugh again, too.

My thoughts and prayers are with you.

Maggie, Donor Mom

*"This book seems to be
so universal that all who grieve
can relate and benefit from it;
whether it be loss of a child,
parent or spouse."*

Pamela Grindstaff
Modesto, CA

Preface

This book was written in the hope that it may help you now and in the months to come. It was written by a donor mother who is also a nurse and a bereavement coordinator. It expresses not only her thoughts and feelings about grieving and growing, but those of other donor families who were willing to share what they have learned from their grief.

The decision made by our donor mother and these families, to allow their loved ones to become donors, was a personal one. It was the right decision for them, as we hope your decision was the right one for you. Some families find that donating has given some meaning to their loss, while others are still undecided.

The National Donor Family Council
of the National Kidney Foundation

*“We knew if our daughter
couldn’t live, both she and
we would want someone else
to have a better life.”*

Barbara Wetzel & Family
Chesterfield, MO

Introduction

This book has been written especially for you, the donor family. You are very special, and what you and your loved one have done is vitally important. You looked beyond your most painful and personal loss with courage and compassion, and were able to extend the gift of life to someone you did not know. For this very special gift, the recipients and their families will always be grateful.

Now, what is important is YOU—and how you are feeling. You may feel alone with no one to share your deep sense of loss. However, you are not alone. You can share with other donor families and with those around you. The pain you are feeling will eventually soften.

This book was written to offer you some simple thoughts about the loss of someone you love. In developing this book, we have spoken to many donor families. We thank them for allowing us to share their thoughts, feelings and personal experiences with you.

This book will also try to answer some of the questions you may still have about your loved one's donation, and it will direct you to people in your area who can help answer your questions. We have also compiled a list of other resources that may comfort you or help you to better understand the way you are feeling.

Last, we hope this book will help you as you begin to live without someone you love.

Who Are Donors and Their Families?



Donors and their families are very special people, like you, who have given a unique gift.

Thousands of men, women and children become organ and tissue donors every year. Donor families are also those who wished to donate, but for some reason were not able to, for it is not so much what is donated, but the *commitment to donate*.

Donors are of different ages, cultures and religions, yet they have common traits. Usually, they are healthy individuals who die suddenly and unexpectedly. Some gave careful thought to donation and made a conscious decision to donate to enhance or extend lives or to help with research efforts. Some signed a donor registry or card or discussed their wishes with their families. Others have families who made the decision for them at a very difficult time.

All donors have special families like you, who at a most difficult time made the decision to donate. Donors leave behind family members and friends who struggle with their loss, knowing that, in the midst of their tragedy, sorrow and grief, other lives have been improved or saved through transplantation and research.

If Your Loved One Was an Organ and/or Tissue Donor

Many of us had to say goodbye quickly, without preparation. This experience was extremely difficult, perhaps the hardest thing we had to do. But knowing the person was an organ and/or tissue donor gave many of us hope.

One donor can benefit many people. Organs that can be transplanted include the kidneys, heart, lungs, liver and pancreas.

Tissue donation offers the opportunity to perform a humanitarian service to many. Donated corneas can restore sight, heart valves can replace those that are damaged, bones can prevent amputations, veins can restore blood circulation, tissue can repair tendons and ligaments, and skin can help burn victims heal.

Donation after Cardiac Death

Donation after Cardiac Death (DCD) means that after the heart has stopped beating, and death is pronounced by a physician, organs and tissues may be recovered and offered for transplant.

A person with a severe neurological injury, such as a stroke, bleeding into the brain, trauma, or suffocation, may be a DCD donor.

Understanding Brain Death

We may have seen a heartbeat on the monitor and a chest moving up and down; we may have left our loved one looking flushed and feeling warm—in fact, looking as if he or she were only sleeping.

But the doctors and nurses told us that our loved one had suffered brain death. And brain death is death.

When brain death occurs, the brain is no longer able to send messages to the body to make it work—to breathe, regulate its temperature and perform other vital functions. When the lungs do not take oxygen into the body, the organs and tissues die. A machine called a ventilator brings air (oxygen) into the body to keep the organs and tissues working. That is why our loved one looked flushed, warm and alive.

The death of our loved one was determined by sound and accepted medical guidelines. Several medical tests were carefully conducted to confirm our loved one's death. Death must be determined before donation can occur.

After death has been declared, the recovery of organs takes place in the operating room. The kidneys, heart, liver, lung, pancreas and small bowel can be donated and save the lives of thousands of waiting recipients each year.

If you have questions about brain death or your loved one's donation, you can request a free copy of *Brain Death: A Simple Explanation* by visiting the NKF Store at www.kidney.org/store.

If Your Loved One Donated to Research

Not all organs can be used for transplantation. If they can't be transplanted, organs and other tissues can be donated to research. These donations help researchers find new ways to treat diseases, such as cancer, diabetes, heart disease and kidney disease, along with many others.

Research affects untold numbers of patients who can benefit from the medical advances. In addition to major organs, tissues such as bone, muscle, tendons, and skin are needed for medical research, pharmaceutical studies, and medical education and training programs.

If You Receive a Bill by Mistake

Donor families are never charged for the donation of their loved one's organs or tissues. Therefore, you should never receive a bill for any of the procedures related to donation. Sometimes hospitals send part of a bill by mistake. If you receive any charges that you think should not be part of your bill, call the recovery organization immediately (their number may be listed on the first page of this book or you can contact the NDFC to help you find them).

Do Transplants Really Work?

Like other donor families, you may be wondering whether the gift of your loved one's organs and tissues will actually enhance or extend the life of another. Consider the following: Millions of people have benefited from organ and tissue transplants. Success rates for heart, liver, heart/lung, kidney and pancreas transplants continue to improve each year.

The transplantation of corneas results in improved or restored vision in nearly all of those with reduced eyesight. Transplanted skin tissue is used to help burn victims. Bone grafting is performed to replace bones destroyed by tumors, trauma and infection. This allows limbs to be spared that might otherwise have to be amputated.

Organ and tissue transplantation works. Transplantation brings help and hope to thousands of people each year. Your gift and that of your loved one is what makes transplantation possible. Organ and tissue donation is literally a "gift of life."

*“By helping another, our grief
became a little lighter and the
recipients’ lives a little brighter.”*

Michael & Deborah Romanski
Glastonbury, CT

When Our Loved One Died... Thoughts from Donor Families

When our loved one died, our world fell apart and we were changed forever.

There was little or no time to say goodbye...to say I love you.

We were overwhelmed by the suddenness of death. Shocked. Numb. We know now what is meant by the expression, "It took my breath away."

The unbelievable had happened...we felt out of control. We felt isolated and totally alone. It wasn't real, it wasn't happening to us, it couldn't be. We were sure we'd wake up one morning and our loved one would be there.

If you feel this way, or have experienced any of these feelings, perhaps the thoughts we're about to share will help you. We hope they do.

The National Donor Family Council asked donor families, "What are some things you have done to help along your grief journey? What has given you comfort or hope?" Some of their responses follow:

We take our "D-Day" and spend it in whatever way that 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. We plan what feels right for us.

–Pat

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...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, while providing me with the space to honor the past.

–Rodney

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

–Bonnie

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

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

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

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

Since his death...I keep busy, 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

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 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

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

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

Grief Is a Natural Response to Loss

Grief is a natural response to the loss of someone you love. You may experience a range of feelings from the time your loved one died to the next several months and years. Because each of us is different, we experience grief in different ways. Please remember that all members of your family have been touched by the death, and there is no right or wrong way to grieve, only your own way.

You may move through the first few months as if you are in slow motion, feeling numb and detached and having trouble concentrating. Life may hold very little meaning. You may even feel as though the death hasn't happened.

These types of feelings may continue for weeks, months or longer. You should remember that they are natural. There is no time limit for grieving to be over and acceptance to begin. Grieving takes much longer than many people want to believe.

Please remember that you don't have to grieve alone. You may find support from people around you—family, friends, clergy, doctors, counselors, support groups or from other people who have suffered a similar loss.

Guilty, Sad and Lonely

Some of us felt guilty and somewhat responsible for the death of our loved ones. We loved and cared for them. We may think we should have done something more to protect them. And some of us may not have had a loving relationship and may feel guilty about that.

Others of us felt very sad and lonely. Sometimes, even when surrounded by friends and family, we still felt alone. We sighed frequently and cried often. Just when we thought we could never shed another tear, the pain started to rise, as if from our very depths, and we felt a tear roll down our cheeks.

Some of us fought off the tears. Although we knew that crying could help, we were afraid to cry, afraid to feel the pain. Some of us were afraid that if we started crying, we'd never stop, and we'd lose control completely.

These responses are natural. It's part of getting through grief. Let it happen. Friends and family are often afraid they will make you cry, so they may avoid talking about your loved one or even saying his or her name. You need to let friends and family know when you want to talk. You may cry, but they need to know that is what you need to do. You may even find that they have similar feelings and will cry with you.

Exhausted and Depressed

Many of us found our grief to be exhausting. We felt tired all the time—grieving takes a lot of energy. We slept poorly. Appetites changed. Some of us ate more, some ate less.

However, some of us discovered we had energy to burn. We felt we had to keep moving, doing something all the time. We feared that if we stopped, the pain would overwhelm us.

Some of us couldn't concentrate on anything. We couldn't finish anything we started. We walked around in a daze. We thought about our loved one all the time. We wanted to talk and often thought that no one would listen.

We were depressed. Some of us felt that life just wasn't worth living and nothing mattered. Sometimes we "felt" the presence of our loved one or thought we saw or heard them. We were frightened that we were actually going out of our minds, that our pain would never go away.

Please know that we understand your feelings and we felt this way, too. Over time, though, our feelings changed. If you feel that you can't go on, that you're overwhelmed by how you're feeling, share your pain and ask for help. You deserve that help. Please do not try to get through your grief alone. We've all needed help along the way.

Am I Losing My Mind?

By Charles A. Corr, PhD, CT. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Winter 2006.

After her son died in an auto accident, Joan and her husband agreed to follow the wishes that he had previously shared with them about donating his organs and tissues. Joan felt good about that decision.



Just a few weeks later, however, Joan told her sister, Janet, that she felt like she was losing her mind.

It was almost as if she could not recognize herself or her life anymore. So many things she had taken for granted, like being a mother and raising her children, now seemed different and strange to her.

Like some other donor family members, Joan was unsure if she had done the right thing in agreeing to donation. She knew she had only carried out her son's wishes. Still, the shock of his death still seemed to throw Joan off balance, and she could not help but wonder if she had made the right decision.

Joan had always had faith in her abilities, but now she wondered if she could trust her judgment. When she set out to do things, she could not remember what she wanted to accomplish. She would go on shopping trips, only to return home wondering why she had bought so many unnecessary items. It was difficult for her to concentrate on simple tasks and conversations. She angered over trivial matters or cried for no reason at all. She found it hard to be with other people, especially at family gatherings, where everyone wanted to be happy, but she knew she couldn't just stay home, sitting and staring at the television, without even realizing what was on.

Finally, she summoned up her courage and asked Janet: “Am I losing my mind?”

Janet knew these were not her sister’s typical behaviors and realized Joan was troubled by what was happening. So she helped Joan make an appointment with the family services coordinator at the organ recovery organization that helped arrange the donation.

Katherine, the coordinator, assured Joan that she was not losing her mind. She explained that many people who encountered a major loss in their lives experience some type of disorientation. They often find it is difficult for them to cope with things that had previously posed no problems at all. Everyday affairs might seem unfamiliar and alien to them. They might even begin to mistrust their own abilities and behaviors.

Coping with a loss like the death of a son, dealing with one’s grief reactions to that loss and finding ways to go forward with healthy living can be quite difficult, especially when the death occurred suddenly and unexpectedly.

Katherine encouraged Joan to be patient and accept the help that was available to her. She praised Janet for being available to her sister. Katherine also suggested Joan join a support group for donor family members or try individual counseling.

Above all, Katherine reported that from her experience, she could assure Joan that very few people really do lose their minds from bereavement. They certainly do encounter challenges and difficulties, but that is to be expected when one is confronted with a major, life-changing event. In fact, Katherine told Joan that she had been impressed by the courage and strength shown by so many donor family members over the years, who have learned that they can rise above those challenges and find ways to honor their loved one’s legacy by not giving up on their own lives.

Anger as a Grief Reaction

By Suzy Ball, RN, MHS, Donor Family Member. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Summer 2008.

Anger is a powerful emotion. Although everyone experiences anger, it is not considered acceptable by society. Anger during grief can be misperceived by many, especially those who experience it. For donor families, 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 and 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 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 family member, 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.

Grief and Spirituality

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 find themselves questioning their beliefs or seeking new answers. Others may begin to explore their spirituality for the first time.



The National Donor Family Council asked donor families, “**Did your experience with death and loss lead you to question your religious or spiritual beliefs? Is your relationship with God (or religion/spirituality) different from before? Have you become more or less spiritual or religious than you were before? Have your beliefs changed in any way?**” Some of their responses follow:

We lost our daughter Alison almost 10 years ago. Our relationship with God became more personal and direct after her death. 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

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

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

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

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

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

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

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

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

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

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

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

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

*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

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

“We find it very difficult to ask for help. If someone would offer to lend us their shoulder we’d use it, but it seems like others aren’t sure how to offer and we can’t seem to ask.”

Michael & Brenda Winner
Arcadia, CA

What Can Help?

Everyone grieves differently. What helps and comforts you may not help another. We found that people often tried to help us in ways that were right for them but wrong for us.

Learn to lean on your family and friends. Don't be afraid that you are bothering them. Let them know the kind of help you need. Sometimes they are afraid to help, afraid they'll say or do the "wrong" thing. Ask not only for help, but for friendship and understanding. Seek out those who allow you to share your feelings with them and who can give you the comfort you need. Sometimes these people are the ones you least expect might help you, such as new friends or support group members.

Find a special way to remember your loved one: wear a special piece of jewelry, plant a tree, start a memorial fund, donate a favorite book.

Be good to yourself. Try to do something special just for you. Buy a crazy hat, plant a special flower, take a walk or visit a friend. Planning will often give you a reason to begin each day.

Good Physical Health

Take care of yourself physically. Be aware of any physical symptoms of grief, such as headaches, muscle aches, or stomach pains. Sometimes our emotions create physical responses and deplete our immune systems. Make an appointment for a physical to see if you are healthy. Plan a healthy diet and exercise.

This may help you to sleep better and feel better.

Avoiding Drugs and Alcohol

Drugs and alcohol are depressants and don't help. If your doctor orders medication for you, be sure that he or she is aware of your loss and knows if you're already depressed or feeling low.

Rest

Try to get enough rest. Remember, grieving is exhausting and you need all your energy to get through each day. If you're not sleeping well at night, rest at other times. You may find it helpful just to put your feet up or close your eyes. Reading, exercising or warm milk may also help you sleep better. Contact your physician if you feel you need medication to help you sleep.

Say No

You may find that you cannot do all that you want or all that others expect you to do. Learn to say no. It doesn't mean forever, it's just until you're feeling stronger. When people are unsupportive, or say things about how you should feel, simply tell them, "That's not how I feel."

Get Away

Try to go away for a few days or even a few hours. Being away can help, and you may return with increased energy to face your grief. But try not to make major changes in your life initially. Give yourself time.

Find Answers to Your Questions

Understanding or talking about what happened, over and over again, is not uncommon and may be helpful. Ask questions of the police, doctors, nurses, clergy, family or friends if you still need answers about the death or hospitalization of your loved one.

Talk and Share Your Thoughts

Talking may be a healing force. Talk to others who have experienced a similar loss. Join a support group or talk to another person who is further along in his or her grief. Knowing that other people have lost someone and were able to go on with their lives gave us the hope we needed. Some of us found that writing about what we were feeling was easier. We wrote stories, poems and articles about our loved ones. Some of us also painted pictures or created something to remember those we had lost.

Seek Information

Read about grief. It may help you to know that what you are feeling isn't unusual—others have felt the way you do. A list of helpful books and pamphlets starts on page 63.

Find Support

It may help you to talk or meet with your family doctor, counselor, clergy or a close friend. Talking to someone you trust and whose advice you can rely on—and talking with that person regularly—may give you the extra support you need during this difficult time. You can check with local places of worship, hospitals, or funeral homes for more information about professionals or support groups.

Get Involved

Some of us have found it helpful to get involved in advocating for donor families or raising awareness about donation and transplantation. Visit www.kidney.org/advocacy to learn how to become an advocate

Surviving Special Days

Holidays, birthdays and anniversaries can be difficult. You may find that the time leading up to the special day is often more difficult than the day itself. You want to celebrate with your family and friends. Or you might find that celebrating the occasion may be too painful, especially early in your grief. You can simply say no or change your traditions to see if that helps. Some of us continue to plan something special to remember our loved ones. We light a special candle, bake a cake, plant a flower or give a gift to a child. This helps us keep our loved ones a part of our celebration.

Be Patient with Yourself and Others

Don't be too hard on yourself. Some days will be more difficult than others, but they will get better. Take one minute at a time. The minutes will slowly turn into hours, and soon an entire day will go by, when it will be okay. But realize that there will be some hours, days and weeks that are easier and then suddenly, out of the blue, you may feel overwhelmed with emotion again. This is natural. Be gentle with yourself. The death of your loved one isn't something you get over; instead, you learn to live without him or her in the best way that you can.

Coping with Sleep Difficulties While Grieving

By Jeff Feldman, PhD. Reprinted (in part) from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Summer 2005.

While sleep is a basic human need, and almost everyone experiences occasional sleepless nights or periods of poor sleep, about one third of adults report chronic sleep difficulty. Sleep problems are most likely to occur

in times of stress, illness or a traumatic life experience, such as loss of a loved one. Sleep difficulty following such a loss can develop into a chronic problem. This can make the daily ritual of drifting off to sleep an added nightmare for those who are grieving. Sleep deprived individuals are more likely to develop serious illness or be involved in accidents.



The techniques in this article are not a “quick fix” like sleep medications but will be far more effective and safe in the long run. It is important that you give yourself at least two to four weeks to see positive results and 10 to 12 weeks for significant long-term improvement. It is important to not give up after one or two nights.

The first and most important steps to take involve getting control of your sleep cycle. While you cannot always control what time you fall asleep, you can control what time you wake. Most Americans get too little sleep during the week and try to catch up on weekends. They sleep late Saturday and Sunday morning and, understandably, then have difficulty getting to sleep Sunday night. The most important rule of sleep hygiene is to get up at approximately the same time each morning, including weekends. While it does not have to be to the minute, you should probably not arise more than an hour later on weekends. This can be particularly important following the death of a loved one, when normal routines are disrupted, and it can be difficult to motivate yourself to get out of bed. Also, to avoid disruption of the sleep cycle, do not take naps of over one hour during the day. This is different than taking 15 to 20 minutes to relax or meditate.

To be able to sleep at night, you need to feel relaxed and sleepy. The nervous system is activated when you are anxious, nervous or worried. This, of course, is often the case for individuals who are grieving. You might “keep it together” during the day at work or with family members, but once you go to bed, you can’t help feeling intensified grief or worrying about all that you need to take care of and deal with on your own.

Furthermore, after the loss of a loved one, there is a pervasive sense that things are just not right, resulting in a general sense of hyper vigilance. You might hear noises you previously would have ignored and feel generally unsafe and vulnerable. So, the second most important rule of sleep hygiene is to not get into bed until you are relaxed and feel drowsy or sleepy. Personally, I find it best to read something that is not emotionally stimulating prior to going off to sleep.

If you find that no matter how sleepy you are, you start worrying or grieving once you hit the bed, then it is important to set up your worry or grieving time earlier in the day or evening. In other words, don't try to "keep it all together" until bedtime. Set aside 20 to 30 minutes of grieving or worry time well before bedtime. Write down whatever problems or worries you have and whatever you can do about them. Then, if such concerns or worries come to mind when you are trying to sleep, tell yourself that you already have worried about them, have done whatever you can about them and can further think about them during your worry time tomorrow.

If you are in bed for 20 to 30 minutes and cannot go off to sleep, get out of bed and return to reading or doing something you find relaxing until you feel drowsy. If your mind is extremely active or you are agitated, it is probably best to leave your bedroom altogether. Lying in bed tossing and turning night after night creates a situation where the bed becomes associated with tossing and turning. It is not uncommon for individuals to be very sleepy, but as soon as they go to bed, they become wide awake because the bed has been conditioned to this adverse tossing and turning. In this way, the bed has become a trigger for this experience rather than a pleasant and restful place to go off to sleep.

Make your bedroom as conducive to sleep as possible. Keep the room dark and quiet with a comfortable temperature. While individuals vary in their preferred room temperature for sleep, most individuals

sleep best at a temperature of about 68 degrees. A running fan, air conditioner, or pleasant music in the background that might mask out intermittent noises can be helpful at preventing disruption of sleep.

During the grieving process, it is not uncommon to want to stay in bed and eat, watch TV, talk on the phone or do work that you have brought home. It is important to use the bed only for sleep, to develop the association that the bed is for sleep and not for such waking activities. Similarly, avoid sleeping in other areas around your home. If you feel yourself getting sleepy, make sure you get up and get yourself into bed. It is not uncommon for individuals to fall off to sleep in a recliner while reading or watching television, get up, and by the time they get to the bedroom, they are awake and have difficulty going off to sleep.

For many individuals, the difficulty is not with falling asleep, but with waking up in the middle of the night and not being able to go back to sleep. The majority of adults wake up at least once in the course of the night. It is important not to get upset when this happens. Instead, it is best to get up, not turn on a bright light, and make your way to the bathroom if you need to. Try to go back to bed and go off to sleep. If after 20 to 30 minutes you are still not able to go back to sleep, get up and do some reading or something else to help you get drowsy again.

To make it more likely that you will be able to sleep, it is important to avoid stimulants and stimulating activity prior to going off to sleep. I, for instance, need an hour and a half after watching a thriller, action movie or many sporting events to be able to wind down, relax and get sleepy. Individuals vary in their susceptibility to caffeine, and it is important for most individuals to avoid caffeine for six to eight hours before bedtime. In addition to caffeinated beverages, such as coffee, tea, colas and many other soft drinks, be aware that chocolate and some over-the-counter medications contain caffeine. In addition, certain health drinks contain substances such as guarana or mate, which are stimulants.

Medications that can have stimulant properties include those for weight control, headaches, nasal congestion, allergies and even some for pain control. While a small amount of alcohol before bedtime might make you drowsy, it is not a good idea to consume significant amounts of alcohol to “knock yourself out.” Alcohol can disrupt the soundness of sleep, generally interfering with the REM sleep cycle, the most restorative stage of sleep. Nicotine is not only a stimulant preventing individuals from going off to sleep, but individuals who are highly dependent on nicotine often wake up due to nicotine withdrawal.

It is also generally best to avoid heavy meals right before bed, and to decrease fluid intake in the hours before bedtime to avoid waking up with a full bladder. Some individuals find that a light carbohydrate snack before bedtime helps them sleep. Others find that having warm milk or another dairy product helps them sleep. A steady daily exercise routine generally enables people to feel more fatigued at night, increases their ability to go off to sleep and deepens nighttime sleep. Exercising causes a rise in body temperature, followed by a sleep-inducing drop in body temperature hours later. Working out in the late afternoon or early evening—four to six hours before bedtime—is probably best, because it gives time for the body to “cool down.” It is important not to exercise just before bedtime to “tire yourself out.” You will stimulate your nervous system and raise your body temperature, making it quite unlikely that you will be able to sleep for several hours.

Sleeping pills might be considered for short term, temporary treatment. Most individuals develop a tolerance to sleep medications, with their losing effectiveness over time. Some individuals, however, develop “rebound insomnia” when they stop taking sleeping pills. Some sleep medication interferes with the deepest, most restorative stages of sleep, making some individuals feel worse the next day.

For some, antidepressant medication taken at night can be helpful, increasing the serotonin level in the brain, which helps facilitate sleep. Check with your doctor to determine if medication might be helpful for you.

Insomnia can be a result of the stress you are experiencing during a turbulent time in your life, which makes it more difficult to cope with everything and anything. Following the loss of a loved one, you are going through many changes that can make you feel out of control. By making changes that enable you to sleep better, you are taking an important first step towards regaining some control of your life.

Nutrition: The Foundation of Self-Care

By Darlene Kvist, MS, CNS, LN. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Winter 2005.

You may ask what your day-to-day nutritional choices have to do with surviving the loss of a loved one. The food that you eat affects your mood, overall health and immune system. When you experience a traumatic loss and ongoing stress, good nutrition becomes critical to maintaining your health and well-being.



Stress and Eating

Stress of any kind, particularly grief, can change eating patterns. When we grieve, food often becomes a secondary concern, even an afterthought. Some people lose their appetites for a while and eat little or not at all. Others eat almost by default, consuming whatever is handy, including sugary or junk foods that they would not eat under other circumstances. Eating is no longer about self-nurturing or even nutrition. We eat to keep going, to distract us or to dull the pain. Most of us know intellectually or intuitively that the sugar or junk food is not helping. Many of us realize that our blood sugar will crash after eating sweets, causing us to feel worse.

The Food-Mood Connection

What is the connection between food and mood? Our cells talk to each other through an elaborate network of chemical communicators, called neurotransmitters. Eating foods with sugar or trans fats (margarine or hydrogenated oils) desensitizes or blocks those neurotransmitter receptors. The well-intended “comfort foods” people bring during a time of loss are frequently high in sugar or processed carbohydrates and are the very foods that create heartburn, low moods and depressed immune function. When this happens, you may experience more pain, depression and anxiety. Short term, you can aggravate an already stressful situation; long term, you can compound health problems.

Stress and Your Immune System

Have you ever thought how stress affects your immune system? Trauma, stress and grief have a detrimental effect on the immune system. While grieving, you may experience frequent colds, cold sores or other viral infections. These viruses may seem bothersome, but if you do not eat healthy enough to rebuild your immune system, and the stress continues for months or years, you become more vulnerable to illnesses, such as chronic fatigue or other immune problems.

Importance of Nutrition

In elementary school, high school, and college we are taught to read, memorize and solve problems, but not how to deal with grief or survive the day-to-day reality of putting one foot in front of the other after a loss. We did not learn how to experience and grow from the loss of a loved one, nor were we taught to support the body, mind and spirit nutritionally during this time.

Grief counselors, clergy, friends and family all try to help us. Culturally, we are trained to seek emotional support. However, until recently, nutritionists have not been part of the support team. While we may recognize the need for emotional help, what about our physical/mental/spiritual health?

A time of loss or of extended caregiving often takes a greater toll on our health than we may initially realize. Have you ever thought that good nutrition is more powerful than anything else you could do for yourself? Eating nutritious, good food is the most basic way to care for your health and well-being.

Nutritional Self-Care Plan

If you are experiencing intense loss, nutritional guidance may help you feel stronger and keep you healthier. Working with clients who have suffered a loss and are grieving, I have formulated several nutritional steps for self care.

- Eat several small meals per day. Five or six may be best.
- Include protein, vegetables, and healing fats (olive oil, butter, nuts, olives) at each meal and snack.
- Limit consumption of coffee, soda and alcohol.
- Drink eight to ten glasses of water per day.
- Avoid processed sugar and carbohydrates. When you crave sugar, slice an apple and spread it with healthy peanut butter (no added sugar or fat).
- To sleep better, avoid sugar, chips, popcorn and alcohol at bedtime. Instead, have a handful of nuts and hot herbal tea.
- Encourage yourself to do nurturing things by cooking a meal that includes vegetables and healing oils, such as olive oil.

Good nutrition is nourishing on every level. Eating healthy will not only help you cope better in the short term, it may also protect you from future health problems.

One Step at a Time

By Rose D'Acquisto, Donor Wife. Reprinted from the National Donor Family Council's For Those Who Give and Grieve newsletter, Spring 2009.

In the weeks and months that followed my husband's death, my life felt like a record playing on slow speed. Exhausted from grief, I spiritlessly did what needed to be done, too wiped out to do anything more.



I felt far removed from the woman who used to have boundless energy for dancing, reading, singing, shopping, cooking and laughing with friends and family.

Two years later, I was desperately tired of feeling tired all the time. A friend gave me the number of a fitness instructor who could suggest ways to get my energy back. I was afraid I'd be told to suck it up and get back in the gym, which made me want to crawl back into bed just thinking about it. Instead, I was told the best thing I could do for myself was to start walking.

At first, I could barely walk to the end of my block. Slowly, I worked my way up to two-, four- and six-block walks. Early mornings were my favorite time. Quiet and still, I could take in the day at my own pace.

Sometimes I cried, letting the tears flow freely, as there was no one around to tell me not to. Other days, I stopped to listen to birds as they trilled brightly, or to smell the dizzying perfume of spring lilacs. And slowly, one step at a time, I could feel myself growing stronger.

That fateful day I walked out of the hospital a widow, I remember thinking how strange the world seemed. The sky never looked so blue, the grass never so green. I saw life, in all its vibrant, shocking, technicolor glory.

On my walks today, I appreciate the way the sun warms my face, how brilliantly blue the sky is and how life—especially my own—has never seemed so precious.

Renewed Grief

By Lani Leary, PhD. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Fall/Holiday 2008.

Grief is hard work. While we work physically, emotionally, mentally and spiritually to labor through our grief, we often come up against sudden, unexpected challenges that renew and add to our heartache.

Grief work can feel close, raw and exhausting, but it can be even more difficult when we experience additional losses.

A sudden, temporary upsurge of grief, or “grief burst,” can happen for a number of reasons. Your reaction can come as a response to the anniversary of the death, a birthday or other meaningful holiday. A favorite season that has special memories may bring back a wave of longing and grief. Or, everyday, small things—smells, sights, sounds—can bring a surge of grief.

Unexpected grief can be triggered when you reach an age that is associated with the death. For example, when celebrating your birthday means living more years than a sibling, you may feel guilt along with renewed grief. An experience such as a wedding or graduation, even if it comes decades after the loss, can trigger waves of grief response.

Additional, subsequent losses can exaggerate and compound your sense of being alone or left behind. Loss of a job, loss of a home, loss of a marriage, loss of mobility or health, the death of a pet or loss of a dream all remind you that you are vulnerable and suffer cumulative losses and deaths in many forms.

For example, when the pet of a deceased daughter dies, you lose more than just a beloved animal. You may experience that as losing an invisible connection to your child and a way to remember her. These additional losses can be devastating because of what they mean to us—not just the loss of the person or object, but also the secondary loss of the link to our loved one.

Each secondary loss requires its own set of grief reactions, from disbelief and anger to the exhaustion that comes from sleeplessness and sobbing. This loss and the renewed grief that you will feel is a long process, and not one event. No one can expect you to move through this at either their pace or quickly because it is “just” a day or a season or a song or a pet. These require an adjustment period. You have to respond to the conflict between the world that you had learned to live in, and one that cannot be.

Others may not understand your renewed grief. It may be helpful to ask your family and friends to respect the disorder and confusion of this renewed grief for you. You can ask them to be with you in a supportive, non-judgmental way so that you can feel all of the painful emotions that surround whatever is causing your grief. That will be your “way through grief.”

How a Memorial Space Can Help a Grieving Person

By Rev. Jennifer Malewski, MDiv, BCC, CT. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Summer 2009.

Creating a personal memorial space is a way of honoring a loved one and inviting positive spiritual feelings into our homes. A memorial space can include anything that reminds you of your loved one. It doesn't need to be huge or elaborate—it can be something fairly simple and unobtrusive, such as a photo, along with a few possessions or symbols of that person, placed on a dresser, bookshelf, outdoor area or other location. It is a sacred space with special articles of remembrance. Many of us have an instinctive need to remember those most valuable to us in an atmosphere of music, candles, poetry, readings, incense, flowers, plants, arts and crafts. This space may be secular, spiritual, religious or a combination of all of these.

The space can be a portable or permanent fixture in one's daily habitat. It promotes the grieving process as normal, fostering good memories of the loved one, providing comfort and giving us a safe place to mourn, pray, read and remember. It lets us express our emotions and can reduce stress, anxiety and depression. The space shows us that grieving is not about forgetting, but rather, it is a sorting process. Its presence allows us to remember with love instead of pain and lets our grieving heal us. One by one we take hold of the things that have become a part of who we are and build ourselves up again.

Hispanic households, Buddhist oriental homes and Zoroastrians' habitats have had memorial spaces in their homes for decades, sometimes centuries. In a 2001 study, researchers found that creating this space is the second most important ritual activity that helps the bereaved. (The first most important activity is designing a remembrance ceremony or celebration.)

Many of us feel comfortable using a memorial space as often as it feels right—daily, weekly, monthly or yearly, on an anniversary date, or on holidays.

For myself, in my simple space are the photos of my mom, dad and only sister, with candles lit at holiday time, a small ceramic angel, a porcelain flower my sister gave me and an embroidered cloth from my mom's family. This is all I need to bring me comfort and good memories. I hope you find what is best for your memorial space and that it brings you comfort and peace as well.

“At the time of our daughter’s death it was very difficult to think and make choices. Now, it has helped our grieving to know that in spite of our tragedy and loss, several other people are blessed with health, hope and the promise of life.”

Rob & Jan Rivera
Denver, CO

Ask for What You Need

By Charles A. Corr, PhD, CT. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Spring 2008.

The death of someone you love is like a cosmic punch in the stomach. It knocks you off balance and drains your energy. After such a major disruption to the normal course of your life, you need the help of caring friends.



Many friends will show up and instinctively do the right things. God bless them. Many others won't know what to do or say, however well-intentioned they are. For these people especially, it is important to ask for what you need.

You may be shy and hesitant to do so, but real friends will welcome your guidance. They want to help, but may not always realize what you need.

You may need practical assistance notifying people about the death of your loved one, answering the phone, making funeral arrangements, preparing meals and helping to make sure you are not overwhelmed.

It is also important to let people know how to behave around you. They may be reluctant to talk about your loved one for fear of hurting you. You may need to encourage folks to mention the name of the person who died so that his or her memory is not lost. Invite them to tell you their stories about that person.

For those closest to you, ask them to be with you and just listen. They don't have to do or say anything. It will usually be enough if they are patient, let you experience and express your grief and allow you to find your own ways to cope. The presence of a caring person can be a balm in this difficult time.

A Husband's Letter to His Friends and Coworkers

Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Spring 2008.

Shortly after the sudden death of my wife Carolyn, I wrote the following letter to my friends and coworkers. I hope that this letter will help give you ideas of how to "Ask For What You Need" from those in your own life.

– Doug Harrell, Donor Husband

Dear Friends and Coworkers,

Thank you all for the outpouring of love and support you've given me and my family over a very trying week. My family is in awe of the way my friends pitched in to make the reception after the service so wonderfully special. Whenever I feel sorrow about losing Carolyn, I will also feel gratitude for being blessed far beyond my worth with friends such as you.

I have never walked in these shoes before, and before this happened, I never knew how to act around someone who had suffered a severe loss.

Given that grief is a very personal experience, perhaps I still don't know, but remembering my discomfort in the past, I want to tell you how you can help me.

If you haven't yet had the opportunity, go ahead and tell me that you're sorry, but after that don't feel a need to act solemn. That's what the visitation and service were for. Now, we are past that stage. You can act normally, talk about absolutely anything, make jokes and laugh. I need that.

We only know that Carolyn died of a heart attack and that it came without warning. We don't know why. Please understand that my choice is to live in the "what is," and not in the "what might have been." Don't be afraid that you might say something that will cause me pain. Although I may not show it, Carolyn is never far from my mind. In fact, my biggest fear is that people will stop talking about her or will feel uncomfortable when I do. The thing that makes me happiest is when people tell me some fond memory they have of her. If you see me and you want to lift my spirits, the best thing you could possibly say is something about her like, "I really loved to hear Carolyn laugh" or "I'm really going to miss her smile."

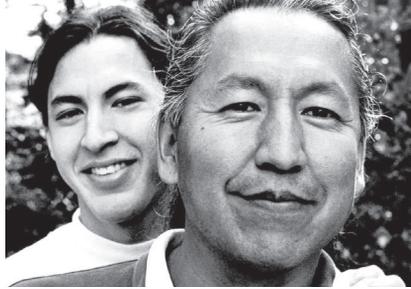
In the last week, three things have softened the blow for me. The first is the love that all of you have shown me. The second is the stories you have shared with me about the Carolyn you knew, and the third is knowing that somewhere out there, she is bringing hope to the lives of others. Because of Carolyn's convictions, someone who was crippled will walk, someone who was blind will see and a child who was dying will live. If you feel as she did, please be considerate of your loved ones and give them the same source of energy and courage that Carolyn gave me on the day she died, by making your wishes [about organ and tissue donation] known to your immediate family.

With Love,
Doug Harrell and family

Healing through Loss: Can Grief Counseling Help You?

By Dr. Robert L. Arnold, EdD, MA, BCPC, CACP, CT. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Summer 2008.

Adapting 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:

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

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 “Find a Provider.” For on-the-spot information, go to www.thehospice.org and click on “Grief and Healing.” There you will find information, resources and downloadable documents on grief and healing.

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. If you need help locating this organization, contact the NDFC for assistance.
- 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) website, www.kidney.org/donorfamily, includes a list of organizations that assist families.

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

Getting the Support You Need

By Lara Moretti. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Summer 2007.

The death of a loved one can be an isolating experience. It can feel like no one understands what you are going through. Even other members of your family can have trouble understanding. And when those around you seem to have “moved on” and gotten back to their lives, you can feel even more alone.



A bereavement professional can offer support, counseling, education and resources to grieving individuals and families. As a supervisor of Family Support Services at the Gift of Life Donor Program, I support our many organ and tissue donor families in all of those same ways. Support groups, however, offer a different kind of support that goes beyond what a professional can offer. There is something important and very unique about being with other donor families. It's about being surrounded by people who have been where you've been, who when they say, "I understand," they really do understand.

One benefit of support groups is the relationships made with others that may extend outside of the group. The death of a loved one affects your relationships with family and friends. Meeting new people who have also experienced a death can help alleviate the isolation that sometimes occurs when family and friends seemed to have moved on and expect you to do the same, or when they do not know what to say.

In addition to reducing your sense of isolation, a support group can teach you new and different ways to cope. Others' shared experiences can expand your own coping methods and problem-solving abilities. The support group is also a safe place to share your emotions. You can express feelings of anger, guilt, sadness, fear and even happiness, and have those feelings validated and supported.

Support groups can also be an important source of information. From community resources to practical tips on getting through a birthday or holiday, you can have a chance to learn from other donor families. Many grieving individuals wonder, "Am I normal?" A support group can provide the opportunity to learn about the complexity of grief from others who are also grieving.

At the Gift of Life Donor Program, there is a donor family support group called Hearts of Gold. The mission of Hearts of Gold includes serving "as a community resource to provide support to donor families through their grief journey." This support is shown in spoken and

unspoken ways. Each new person is greeted with a warm welcome and is given a specially created Donor Family pin. Even if a family comes only one time to a Hearts of Gold meeting, they are always a part of the group and the support is always available to them. If a member starts to cry during our meetings, a box of tissues is passed silently, a hand is placed on a shoulder and heads around the room nod in understanding.

Your procurement or recovery organization might have a support group for donor families, or they can help you find a support group in your area. You might feel nervous about attending that first meeting, but the benefits you will receive from the group and the members will help carry you through this difficult time.

Note: To ask about support groups in your area, contact your organ recovery organization or tissue bank. If you need help locating this organization for your area, e-mail the NDFC at nkfcare@kidney.org.

Grieving Children, Children Grieving

By Celia Ryan, DCSW, LCSW-C, CGT, Clinical Social Worker and Certified Grief Therapist. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Winter 2003.

Our natural inclination is to protect our children from the brutal reality of life, but how can we? It is a nightly fixture on our TV sets, a daily exposure in our communities, and worse, a personal experience at home or at school.

In almost every home there has been loss of some kind. No one needs to die for there to be grief, because any change can produce a deep sense of loss. Divorce, death of a parent or grandparent, a pet's death, a serious illness, job loss or losing a home are clearly major loss events, and there will be expected grief. Smaller but no less significant

losses can be a childhood illness, a disability, a best friend moving away, not making the team and so on. Adults have few guidelines for themselves in grieving; after all, most schools don't offer a class on "How to Help Yourself Grieve," and *Grieving for Dummies* has yet to make the bestseller list! So how can we adults cope with our grief and be appropriately responsive to our children, who are also struggling to make sense of the tragedy in their lives?

Listen, listen and then listen again... with your heart as well as your ears! Try to put your own needs, expectations and prejudices aside to be "present" for your children. They need to know you care, and they need to know that YOU are OK. Often, children "protect" the adults around them at great cost to their own emotional needs. If you are grieving too and cannot attend to their needs right now, try to have another reliable adult around, who can listen and respond.

Recognize there is no "right way" to grieve... Men, women and children have different coping styles and will grieve in a way that works for them. Parents can help by encouraging and giving permission to their children to grieve in a way that is uniquely "right" for each child. Try not to impose adult expectations on them.

Time does not heal... unless grief work is going on. Time in and of itself will not magically take care of difficult feelings and experiences. In time a deep hurt is no longer as "raw" as it once was, but the pain of it will linger and may hinder current relationships or future coping. Parents can help their children by being sensitive to the needs of the child at this time, and later as different developmental milestones are reached. Over time, these needs can and likely will change.

Gender differences... Although everyone grieves, there are distinct differences in the coping styles of boys and girls. A mother describes how her son and daughter coped with the death of a beloved grandparent:

After an emotional weekend, my daughter said, “Mom, I need to stay home today and be by myself.” Her son went to school and promptly got into a fight! Parents can help by being sensitive to the coping styles of their individual children and making suggestions and allowances.

Be proactive... Teachers can be your best support. Make sure the school knows what has happened and keep the communication open. Often we only learn about what could have been helpful after the fact.

Encourage your school and community to provide information, education and helpful resources about loss, just as they do about drugs and alcohol and other important issues. *All of us* at some time will experience significant losses.

Get support... There are many resources in your community to help you, your family and your school when there is a loss of any kind. Knowing where to turn for help is the first step in coping with tragedy.

Helping Adolescents Cope with Grief

The Difference Between Surviving and Thriving Following Family Loss

By Rebekah A. Arsenault, LifeLink Foundation. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Summer 2006.

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 who's 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:

- 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.

Going Home after Donor Events: Letdown or Rewriting Your Address Book?

By Ben Wolfe. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Winter 2009.

When donor families meet for special events, like recognition ceremonies and memorial programs, it can be an emotional roller coaster, with challenging “highs” and “lows.” The events provide opportunities to share stories with others, who validate your feelings and understand when you laugh or cry.



These gatherings provide you with “windows in time” to recapture memories, share how you are feeling today, and know that you are among kindred spirits. Being able to listen to others along their journey and talk about your loved one with “fellow travelers” is an invaluable opportunity.

If you have attended a donor family gathering, you know it can be emotionally uncomfortable, but also meaningful in your grief work. Who are the people who share their lives with you at these events?

They may be people you've never met or people you see only at such events, but they all have unique stories to share, stories that often aren't shared back home.

Grief sometimes deletes people from your address book. Some people no longer call or stop by, but donor family events can add new people to your address book...people who "get it" and give you encouragement and hope.

When you get home from an event, you may be uplifted by the way your loved one was remembered or you might, for a period of time, feel a letdown or sense of being overwhelmed with life's responsibilities. You may be exhausted from the intensity of the event itself. And you may encounter people who don't want to talk about the event or the person who died. You need to ask yourself, "What was my reason for going?" and "What was shared and learned?"

In his book *When Bad Things Happen to Good People*, Rabbi Harold Kushner, whose 14-year-old son died, said, "I had to stop asking WHY it happened. It served no purpose. Instead, I needed to ask myself, now that it happened, what can I do about it?"

Now that you are home, do you need to do anything different with your life? Do you allow yourself to laugh and not feel guilty, knowing that others have felt the way you do and found it possible to laugh again? Do you need to eat better, exercise a little more or do something special for yourself? Maybe it will be journaling, gardening, mentoring a young person or promoting donation in your community.

Carol Crandle states, "It is not through time that one heals, but rather, what you do with the time." After donor family gatherings, it is important to appreciate that the event was a way to integrate your loved one's death into your life story. Sam Cook, a friend of mine and outdoor writer in Northern Minnesota, once wrote, "Go. Get out there. Feel the wind. Taste the rain. Find the magic." My hope for you is when you get home from your next donor event, you will "find the magic." You will remind yourself that you not only helped those around you, but, in turn, you helped yourself.

Ben Wolfe is a Program Manager/Grief Counselor at St. Mary's Medical Center's Grief Support Center in Duluth, MN. He was also an Executive Committee member of the National Donor Family Council.

What to Do with Our Memories

By Barbara Musto, Donor Mom. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Spring 2004.

When my 27-year-old daughter Karen died, one of my greatest fears was that, in time, both family and friends would forget all the beautiful memories of her. I constantly went through dresser drawers and boxes, searching for objects that would bring me a memory.

Then one day during one of these searches, I came across a tiny, pink plastic treasure chest. I heard Karen's voice telling me to open it. Inside were seven of Karen's baby teeth. This was like winning the lottery. I had always felt cheated—when Karen died, no one had thought to cut a lock of her gorgeous black hair. Now I had part of her to hold onto.

One day at a craft show, I came across a wooden box in the shape of a tooth with a little angel mouse painted on it. It was perfect—not only is Karen an angel now, but when she was young her friends called her “Mouse” because she was so tiny. This box, with her baby teeth nestled inside, sits on my bedroom dresser and will always hold a special memory.

When I look back at this time, I realize it was a beginning for me. “Is there something positive that I can do with Karen's memories?” I thought. Today, I do just that: I participate as a speaker in organ/tissue education programs in hospitals, schools and churches. I spread the message about the “Gift of Life,” but I also get to talk about Karen's life and the memories that I hold most dear. Some of the ways we can memorialize our loved ones are:

- Make a quilt square for your local donor family quilt. Many organ procurement organizations have quilts. Families are welcome to use these quilts at their churches, schools and any other local functions.

- Some support groups have started memorial gardens to honor their donors. The United Network for Organ Sharing (UNOS), in Richmond, Virginia, has a memorial garden: National Donor Memorial www.donormemorial.org
- Create a scrapbook or shadow box. You can tell your loved one's life story with these creative projects and always have memories at your fingertips.
- Join a support group. Get together with other families, whether in person, on the telephone or online. We all love to talk about our loved ones—who better to share our memories with than those who understand? We all need someone to talk to.

Each morning when I get up, I thank God for giving me the strength to keep Karen's memories alive. This is what enables me to get through another day and reach out to other families in need.

*“It helps to know that a part
of our loved one is still alive
somewhere in someone else.”*

Renee L. Jones
Montgomery City, MO

As Time Goes on

How do you know when you can put your loved one's clothes or special things away? Some of us did it right away. For others, it took months or years to reach the point where we felt we could do it. We decided that other things shouldn't ever be put away...keeping them out makes us feel better.

When we first experienced our loss, the idea of accepting that loss seemed impossible. Like us, you will never forget your loved one, but peace and acceptance will come eventually. Sometimes we found that well-meaning family, friends and health professionals felt more comfortable if we seemed to be "doing well." "Doing well" has no schedule and you do not have to grieve the way others think you should.

With time, we came to accept the death. With acceptance, we began to learn to live without our loved ones. There comes a time, "the time of missing," when you can talk about your loved one without so much pain. It may be hard to accept this thought now, but someday you'll be able to smile, even laugh about the things that happened between you and your loved one. Try to go on in the best way you can. Know that the relationship and the love you shared with the person you lost will be different, but your loved one will always be a part of you.

As we think of our loved ones, we feel a sense of peace and an understanding that the greatest loss would be never having had our loved one at all. The greatest gift of all is having shared love and life with someone.

*“The gift goes on through the
recipient in every person
he touches throughout his life.”*

Jeanne Potts
Arnold, MO

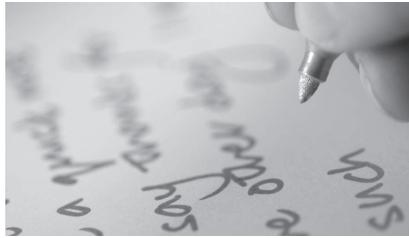
Transplant Recipients

Some donor families want to find out information about their loved one's recipients, just as some recipients may also feel a need to learn about their donor or donor's family. Other donor families or recipients may be reluctant to make contact with each other.

If you want additional information about the recipients or would like to correspond with them anonymously, contact the organization who handled your loved one's donation (their contact information might be included on the first page of this book). If you are not sure who to contact, ask the NDFC for help.

Writing to Recipients

Some of us find comfort by writing to transplant recipients. If you decide to write, here are some suggestions:



- Keep your identity and your loved one's identity anonymous. You may include first names and the state you live in.
- You may wish to share information about your loved one or family, such as the kind of person he or she was or the things he or she liked to do.
- Place the card in an unsealed envelope.
- Include a separate slip of paper with your name and the name of your loved one and date of his or her death so the professionals can identify you.
- Mail your card or letter to the recovery organization that recovered the organ or tissues of your loved one.

The health care professionals will contact the recipient(s) to get permission to forward the correspondence.

Some recipients may write back to you but some may not. It is a personal choice.

For more detailed information about writing to recipients, request a copy of the brochure *Writing to Transplant Recipients* from www.kidney.org/store.

*“His purpose here was fulfilled,
and as he gave in life,
he gave in death.”*

Nora A. Perez
Union City, NJ

Thoughts from Transplant Recipients

To each of you with whom I share a life:

I was comatose and dying when my husband, 17-year-old son and 15-year-old daughter were told that a liver had been found for me—donated by a 17-year-old boy who had lost his life in a sudden and fatal motorcycle accident.

No matter how I try, I cannot imagine my donor family's anguish.

I cannot conceive of seeing my beautiful, vibrant healthy children simultaneously and forever taken from me. Nor can I fathom the pain, the frustration and the ultimate finality of such a senseless and tragic loss.

Perhaps the only thing I can even begin to understand is the courage, the compassion and the great kindness it took to extend life to someone else when their own child's life was so irrevocably lost.

Being an organ and tissue donor is so much more than sharing a heart, lung, kidney, liver, cornea or other tissues. It is, above all, sharing life, sharing love, sharing gratitude for what was and hope for what might be.

Many recipients do not have the opportunity to express their gratitude to their donor's family. Perhaps words are unnecessary, and the best way to say thank you is by living—whether for a day, a week, 10 years or 20—living life to the fullest—joyously, completely, happily-ever-after, one day at a time.

I have been doing just that since February 27, 1982, when my diseased liver was removed and replaced with a healthy organ. Each breath I take is because of the donor who gave life back to me. I give thanks to my donor and the thousands of other donors who gave to men, women and children throughout the world.

On behalf of all of us, bless you and thank you for our second chance.

Joyce S. Willig
Fairfield, CT

Donated Skin Saves Burn Victim

Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Fall/Holiday 2008.

In what should have been another lazy summer day in June 2006, the Pawling family was suddenly faced with a life or death situation.



The Pawling Family

Richard and his two siblings were riding dirt bikes when he and his sister Nicole collided. His gas tank exploded, splashing them

both with burning gasoline. Nicole was burned on her arms, legs and face, while most of Richard's clothes were set ablaze.

"I was not really scared," said Richard. "I remember the pain, and it was hard to breathe. I was wondering if I was going to die."

Richard's brother Chad came to their aid, extinguishing the flames, and his mother Wendy rushed them to the burn center. Wendy recalls, "That is when we really got the eye opener. The doctor told us Nicole would be in for a month or two, but that Richard would be in for three to six months, if he made it."

With third degree burns over 65 percent of his body, Richard's recovery was not assured. "I had a lot of infection issues," he said. "My kidneys shut down and I was on dialysis for a month. My liver was starting to shut down. If people had not donated skin, I believe my chances of survival would have been slim to none. I am glad that doctors have figured out how to use donated tissue to help heal burns, as I am sure this helped save my life."

Parents Kelly and Wendy are justifiably proud of the way their children overcame the difficulties resulting from the accident. Now two years and 26 surgeries after his ordeal, Richard's life is getting back to normal. Making up for lost time, he was able to graduate high school with his class and begin college in the fall.

"Today, my life is back the way it was for the most part," said Richard. "I have a few issues, but I can usually work around them. I worked as a farm hand for the summer and this really helped to build back my muscle tone. In my spare time, I love to ride my motorcycle, swim and hang out with my friends."

Richard adds, "I try to tell people how important it is to donate organs and tissues. So many people aren't aware that skin can be donated. If I could send a message to the family who donated my tissue, I would say "Thanks! You helped save my life.""

Aurora's Story

Reprinted from the National Donor Family Council's For Those Who Give and Grieve newsletter, Summer 2008.

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



Aurora

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 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

Forever Linked

By Jack Fassnacht, Kidney Recipient. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Spring 2006.

Fifteen years ago I received a kidney from someone I will never know, at least by name. For 15 years that kidney kept me alive, kept me feeling good enough to live, to work and to play. I know almost nothing about my donor, except that his or her family possessed the generosity and humanity to think of helping someone else at a very difficult and sorrowful time. And although that kidney has now worn out and no longer helps keep my blood clean as it did for so many years, the person who gave it to me will stay with me until the day I, too, pass on, the two of us forever linked by that act of generosity.

I hope that my life these last 15 years has proven me worthy of such a priceless gift. Since that day in December 1989 when I walked out of the University of Chicago hospital, free from dialysis for the first time in nine months, I have become a father, graduated from law school, helped raise money to build a new church, won a silver medal at the U.S. Transplant Games and given numerous talks about the critical importance of organ and tissue donation.



Jack Fassnacht

Sometimes during those talks I would compare organ and tissue donation to saving a drowning person. No one has to do it by law, but we do it anyway because it is the right thing to do. People and families who donate to strangers are just as heroic as someone who rescues a drowning person, perhaps more so because they do it at a time of indescribable grief and often anonymously.

In the first year after my transplant I wrote two “anonymous” thank you letters to my donor family and, to be honest, I had hoped to receive a letter in return. I did not receive any letters, but that is alright. My donor family had done enough already. They owed me nothing; I owed them my new life. I continue to pray that they have found peace with their loss and perhaps found some small consolation in their decision to donate.

Undoubtedly, my greatest joy since that first transplant has been my daughter Claire. I was unable to have children before the transplant, but afterwards that changed for the better, along with the rest of my life. Claire was born 18 months after my transplant and is now a beautiful 14 year old. She is honest and kind. She plays percussion in her high school band and loves sleeping with her cat, Nellie. She is another happy result of my donor family’s decision to donate.

As I said, that first transplanted kidney wore out in 2005. I guess all things wear out eventually. Nothing is permanent. I have lost my dad and, most heartbreakingly, Claire's mom since 1989. But I still live as good and full a life as I can. Claire, and my first donor, deserve that.

I was fortunate to receive a second gift of life in 2005 from my youngest sister, Paula, who showed a special courage and love in becoming my living donor. So I have four kidneys now. Three people are now permanently and profoundly joined in this 50-year-old body of mine.

I am lucky beyond words—not only to be alive and dialysis free, but to have experienced firsthand such tremendous kindness and generosity.

Since I never knew my first donor family, I consider all donor families to be “mine.” If you are a donor family that has never heard from your recipient(s), rest assured that the community of recipients will never forget your kindness, nor the memory of your loved one. When we attend local tree planting ceremonies in our communities in remembrance of our donors, we remember your loved one too. When we read the names of donors at church services during National Organ Donation Month each April, we pray for donors and donor families everywhere. When we visit the National Donor Memorial in Richmond, Virginia, we pay tribute to the miraculous legacy left by all organ and tissue donors.

You and your loved one are never far from our thoughts. From all of us in the transplant recipient community, thank you for your decision. Thank you for our lives.

The Smile that Love Restored

By Douglas Harrell, Donor Husband. Reprinted from the National Donor Family Council's *For Those Who Give and Grieve* newsletter, Winter 2007.

At the awkward age of 13, when teenagers are already uncomfortable with their bodies, Melissa Nguyen had a bigger worry. A cell bone

tumor was taking over the upper right side of her face. It had to be removed, but so did most of the bone and teeth on that side.

As a young girl, Melissa wasn't able to have her own bone used for her transplant. "I actually did all the treatment options that were available before I had my transplant. My age restricted me from having my own bone removed and transplanted into my face. I was still a growing girl, so they didn't have a choice but to use synthetic bone," she says. Although she was given partial prosthetics, they had to be taken out during meals, making Melissa feel self-conscious about her appearance.



Melissa with her husband Tony

"I have very few pictures that were taken between the ages of 13 and 21. The prosthetics were good, but there's only so much those can do. I always covered my mouth with my hand when I smiled, and there's nothing like the embarrassment of having to take out your teeth to eat when you're on a date."

Although she can now look back on her experiences with a smile, she remembers how often it made her cry. "This may sound ridiculous, but the thing I missed the most was to bite into a homemade caramel apple from Pokey's (a restaurant in my hometown). They only sell them in the fall, and it was something my mom and I did every year together," Melissa says.

Now, after a bone transplant and reconstruction, Melissa has a new smile, a new husband and her life is better than ever. "There is nothing that I can't do. I went back home to visit my family in Iowa, and I had my caramel apple. Also, I got married last June, and there wasn't one picture where I had my hand covering my face."

Touched by her experience, Melissa is now giving back as a transplant coordinator in Hawaii. She sends this message out to her tissue donor and donor family: “The smile I have on my face today is because of you. My confidence and happiness are with me because a stranger gave me a gift that changed my life forever. I am truly grateful and always will be.”

About the National Donor Family Council

The National Donor Family Council (NDFC) was founded by the National Kidney Foundation in 1992 as “The Home for Donor Families.” Comprised of donor family members, friends and professionals, the NDFC supports the needs and expectations of organ and tissue donor families and assists the health care professionals who work most closely with these families. Through dedicated service to the families of those who gave the gift of life, the Council provides a strong, unified voice in meeting their needs and providing a safe haven as they learn to live without their loved ones.

Donor families are families whose loved ones died and donated their organs and/or tissues; families who would have liked to donate, but could not because of medical or other reasons; and families who did not donate, but might have if they had been given the opportunity.

The mission of the NDFC 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. To find out about the resources available to families or to inquire about membership, visit us online at www.kidney.org/donorfamily.

Suggested Reading

Resources for Donor Families from the National Donor Family Council (NDFC)

Please visit www.kidney.org/donorfamily or www.kidney.org/store for available materials or e-mail nkfcare@kidney.org.

Bill of Rights for Donor Families. Outlines the rights and expectations of families whose loved ones have died.

Brain Death: A Simple Explanation. Defines and explains brain death in a comprehensive yet comforting tone. Available in English and Spanish.

Donation after Circulatory Death: A Basic Explanation for Donor Families. Defines and explains circulatory death and the organ donation process.

The Grief Journey: The Death of a Spouse or Lifetime Companion. A resource for those who have experienced the death of a husband, wife or life partner.

Honoring Each Other's Grief: Nurturing a Relationship While Coping with the Death of a Child. When a mother and father grieve over the loss of their child, it's often not in the same way, and they should be aware of the differences in mourning.

Tissue Donation: Your Loved One's Gifts. Explains the tissue donation and transplantation processes.

Writing to Transplant Recipients: A Simple Guide for Donor Families and Living Donors. A simple guide that assists donor family members with writing to transplant recipients.

Your Child, Your Friend: When an Adult Child Dies. This booklet was written by a grief expert to help donor parents understand their particular bereavement experience.

For other reading suggestions, visit www.kidney.org/donorfamily.

Bereavement Resources and Support Groups

The **National Donor Family Council** has compiled and reviewed a list of organizations and websites to create a comprehensive bereavement reference for you and your family.

Please visit www.kidney.org/donorfamily.

Our Heartfelt Thanks

The officers, volunteers and staff of the NKF wish to thank the following donor families for sharing their thoughts and feelings with us as we developed this book. We could not have done it without them.

Special thanks to the hundreds of families who have evaluated this book. We are forever grateful. Special thanks to our donor mom, Maggie Coolican, her husband Don, and their family for their personal commitment and dedication to helping donor families, and for sharing such a personal part of themselves with us.

The National Kidney Foundation also wishes to express its sincere appreciation to its Organ Donation Education Task Force and in particular the following individuals who were instrumental in the development of this book:

Margaret B. Coolican, RN, MS, CDE
Sue M. Dunn, RN, BSN, CPTC
Louise Jacobbi, CPTC, CCTC
Michelle Morse, RN, CCRN
Ellen B. Rudy, RN, PhD
Ginny A. Travitzky, RN, BSN, CPTC
John Davis
Gigi Politoski
Kathleen Casey

Additional thanks to the following individuals and organizations who provided input:

William Bennett, MD
Charles Corr, PhD
Marilyn Crespo
Ken Doka, PhD
Dom Albi Associates, Inc.
William Faraclas, MPH
Jackie Grogan
Reverend Ed McRae
Lucy G. Nile, MA
Therese Rando, PhD
Mark Reiner
June Stark, RN, BSN, MEd
Edee Vassar, BSN, RN
Sara Rich Wheeler, RN, BSN, MSN
Joyce & Robert Willig and Family
Chaplain Skip Wisenbaker, MAE, FCOC
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