

For Those Who Give and Grieve



A quarterly newsletter for donor families, published by the National Donor Family Council of the National Kidney Foundation, to offer information about grief and support.

For Those Who Give and Grieve is provided to all families at no cost.

Summer 2005

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

Volume 14, Number 1

coping with sleep difficulties *while grieving*

By Jeff Feldman, PhD

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,

minutes), sleep maintenance insomnia (difficulty staying asleep), or poor quality of sleep. In all cases, symptoms can include daytime sleepiness, impaired memory, difficulty with concentration, slow thinking, irritability, depression, erratic behavior and poor health.

The behavioral techniques to be discussed in this article are clinically proven to have a 75 to 80 percent success rate. They 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

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with insomniacs having twice the number of auto accidents as individuals who have normal sleep. One study showed that people who slept fewer than six hours each night had a 30 percent higher death rate from cancer, heart disease, stroke and all other causes than those who sleep seven or eight hours a night.

Chronic sleep problems can be experienced as sleep onset insomnia (difficulty falling asleep within 30

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 go off to sleep, you can control what time you awaken. 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. They start Monday morning sleep deprived. The most important rule of sleep hygiene, then, is to get up at approximately the same time each morning including weekends. Do this regardless of how much sleep you have gotten the night before. 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 during the day. This is different than taking 15 to 20 minutes to relax or meditate. Naps of more than an hour throw off your sleep cycle, making it difficult to go to sleep at night.

To be able to sleep at night, you need to feel relaxed and sleepy. This involves activation of the calming branch of the nervous system, the parasympathetic branch. The alarm



Jeff Feldman, PhD

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branch of the nervous system, the sympathetic branch, 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 that alarm reaction activated, with 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. Reading something professional or technical tends to help me to refocus my mind from any personal problems, difficulties or concerns, and within 10 to 15 minutes my eyes get so heavy I can no longer focus on the page. At this point I get into bed and I find myself able to quickly go 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 20 to 30 minutes and cannot go off to sleep, get out of bed and return to reading or to 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 aversive 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.

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FOR THOSE WHO GIVE AND GRIEVE

For Those Who Give and Grieve is published quarterly by the National Donor Family Council of the National Kidney Foundation (NKF). Opinions expressed in this newsletter do not necessarily represent the position of the National Kidney Foundation. The NKF reserves the right to edit all submissions. Please contact the NKF for article submission guidelines or permission to reprint articles.

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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

trying 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 get drowsy and go off to sleep, it is important to avoid stimulants and stimulating activity

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

By making changes that enable you to sleep better, you are taking an important first step towards regaining some control of your life.

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. It is important to know that in the course of the night, one goes through approximately 90 minute sleep cycles. In each sleep cycle, there are five stages of sleep, with the last being the REM stage in which you dream. Following the REM stage, the brain will nearly awaken to be certain that everything is okay and then initiate another 90 minute cycle. Individuals will often awaken feeling alert, which is normal in the course of the sleep cycle. Waking up without your partner is also an obvious source of distress and emotional arousal. It is important not to think that because you are feeling awake, there is no point in

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

carbohydrate snack before bedtime helps them sleep, because carbohydrates have shown to increase brain serotonin. Others find that having warm milk or another dairy product helps them to sleep due to the l-tryptophan found in dairy products. It is important to know that if, like most people, you are trying to manage your weight, food consumed late at night tends to be more easily converted to fat since you are not active and burning those calories. A

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Donate Life License Plates Pick Up Speed

By Rich Mullane, Donor Father
National Donor Family Council Executive Committee Member

Donate life" license plates are already available in some states, and now New York has been added to the list. The legislation that paved the way for the plates was spearheaded by a Long Island politician, Assemblyman James Conte. Assemblyman Conte had a good reason to push for this special license plate. He is a kidney recipient and he wanted some way to show his support and to increase public awareness of organ and tissue donation.

Well, as far as this writer is concerned, it is working. I have three of the new license plates on my family vehicles. When my 19 year old son, Rick Jr., died on March 6, 2000, he donated to 84 people in 24 states. That in itself was a miracle—84 people! Since we

put the plates on our cars, many people have asked us about them while at local shopping centers and schools. We tell them about our son's donations and how part of the cost of the plates goes to a special fund to enhance donor awareness. They all have said they will sign up on the New York State Donor Registry online and will consider getting a license plate. One man actually pulled his drivers' license out of his wallet in the parking lot and signed the back as a donor.

As many organizations all over the country try to find creative ways to increase donor awareness, using cars as moving billboards

is a great idea. There are so many cars on the roads every day, and having "Donate Life" on the front and back of them is a terrific way to get the message out.

I was lucky enough to get "Rick 1", "Rick 2", and "Rick 3" for my cars, so it is even more special for my family and me because not only are we getting the word out on donation, but we continue to keep our son's memory alive. Check your local department of motor vehicles to see if you have "Donate Life" license plates in your state; if not, contact one of your local legislators to start the ball rolling. We have to display registration plates on our vehicles anyway, so why not get them to promote organ and tissue donation!



Have You Ever

By Shelley Jenks, Donor Niece, in honor of her Uncle

Have you ever loved someone
so deep inside,
That when they were gone forever,
it was hard to get them off your mind.
Have you ever cried so much that
it hurt to move?
Have you ever not wanted to believe
something, although it was easy to prove?
Have you ever wanted to be with
that person so bad, that you just
thought of dying?
Have you ever told someone that you
were fine, although you were really lying?
Have you ever thought about that
person so much, that it made tears
run down your face?

Have you ever had to go to that
one very depressing place?
Have you ever wondered if angels
are really there . . . or have you ever
just not cared?
Have you ever just wanted to fall
and never rise on your feet?
Have you ever felt so bad that now
this person is gone forever, you might
have someone new to meet?
Have you ever thought that one day—
you'll be gone forever?
Have you ever thought that, then,
you both can be angels together?

R.I.P. Uncle Mike



The 100TH ANNIVERSARY of the First Corneal Transplant

THE YEAR 2005 MARKS THE CENTENNIAL OF THE FIRST SUCCESSFUL CORNEAL TRANSPLANT by Dr. Eduard Zirm in December 1905. This one event demonstrated that a successful corneal transplant could restore vision. Many people have contributed to and built upon Dr. Zirm's work, creating our modern system of eye banking which has restored sight to more than one million people in the United States.

Born in 1863 in Vienna, Austria, Zirm studied medicine at the University of Vienna. He worked in ophthalmology at Vienna Univ-Augenklinik and was eventually offered a position at a newly formed eye clinic in a rural area of Austria,

now the Czech Republic. While there, he founded what would become the largest eye clinic in the area. During his years in practice, Dr. Zirm conducted thousands of cataract surgeries along with a number of cornea transplants.

In 1904, a man named Alois Glogar experienced burns to both eyes, leaving him blind due to the corneal injury. A year later, Glogar was brought to Dr. Zirm's clinic. At the same time, an 11-year-old boy, Karl Brauer, was in an accident which left him with metal pieces in his eye. Attempts to save Brauer's eye were unsuccessful. Dr. Zirm then enucleated the damaged eye—he removed the corneal tissue

for transplantation into Glogar's eyes. While complications developed in one of Glogar's eyes, the other eye remained clear, allowing him to see and return to work.

The Eye Bank Association of America (EBAA) plans to commemorate this centennial throughout the entire year. The EBAA has created a Web site that provides pictures, information and a listing of national and local events as well as the updated "Hall of History," which outlines the history of eye banking and the EBAA. You can view this information at

<http://www.restore sight.org/100thanniversary.html>

we fondly
remember



Donald A. Menning
May 31, 1939 –
January 15, 2002



*Kimberly Creel
Perruchon*
April 8, 1969 –
December 18, 2004

*A heartfelt thanks
to all cornea donors
and their families
for providing the gift
of sight to so many
grateful recipients.*



thoughts *from donor families*



Patrick and Virgilene

Remember Me

Submitted by Virgilene Gibonez

As the great big kid at Heart...
With the twinkle in my eyes
The way I always took my part.

Remember Me...

And the ability I had...
To laugh at something funny
And to cry at something sad.

Remember Me...

As the best Dad I knew to be...
My Love for my little Girl
For no other meant more to me.

Remember Me...

Playing and caring for my Daughter...
My best days were shared
And how Proud I was to be her Father.

Remember Me...

As you look in Marlee's face...
With the same twinkle in her eyes
She is my Legacy of Grace.

Patrick F. Giboney
Aug. 15, 1966 - Nov. 5, 2000

Poem

from a donor's sister

In the quiet of the night,
I held you in my arms
Knowing it was the last time,
I savored the beauty of your face
My heart ached with sadness so deep,
disbelief, disbelief
I touched your hand, soft, warm,
if only it could be that you were sleeping
but I knew it was time to say goodbye
I kissed you over and over,
I smelled your hair
Constructing a memory to carry with me
I whispered "Goodbye, Sister,
I love you" and
I promised to take care of your babies
Then I realized, *your babies*,
and I cried an ocean

We walked behind your bed as they led
you away

I held up your devastated daughter,
we walked together

Down the hall, to the elevator
Goodbye forever, forever

—Regina's Sister

Check it out on the Web

National Donor Family Council Writing Workshop

Have you checked out the new Writing through Grief Workshop? It's a discussion group on the NDFC message board in which families are invited to share writing prompts, journaling tips and ideas for capturing special memories. We will share articles and links to Web sites about writing. Sign up today on the NDFC message board (www.donorfamily.org) and begin sharing your writing ideas.

the privilege *of caring*

By Cyndie Colarusso, RN, BSN, CPTC, CTBS
Donation Support Coordinator, Osteotech

“May our tears of sorrow be your tears of joy” was the message inside the card. The card was then lovingly pinned to a basket of flowers, just purchased at the hospital gift shop. In a few short hours, that message and those flowers would accompany the most precious gift of the donated heart of a newborn. Soon it would be on its way to be placed into the body of another child, clinging to life in a faraway place.

In response to tears of sorrow and in anticipation of tears of joy, compassion was everywhere that day. In the midst of the darkest

hours of their lives, parents faced with the death of their child, whose life had been measured in minutes, acted in compassion for a child who was not their own. A long list of professionals wiped away their tears and put their skills to work to honor the small life that had passed and to preserve the small life that hung in the balance. Simultaneously, hope was lost by one family and transferred to another through the gift of donation.

A privilege is something granted to some people but not to everyone. A handful of people

had their breath taken away by a simple message and a profound act of compassion on that day. There are others, too, who experienced that same sense of awe when you momentarily transcended grief and loss for the benefit of a stranger. Those who were touched by the gift you gave on behalf of your loved one now understand the power of the human spirit in a way that few people do. That is a privilege.

Thank you, donor families, for the privilege of knowing you.

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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 try 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 them 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. Furthermore, some tricyclic antidepressants have the additional benefit of having an initial sedative effect. Check with your doctor to determine if medication might be helpful for you.

Overall, it is important not to label yourself an insomniac or worry about sleep difficulty. Sleep on any particular night is not absolutely essential, and one sleepless night will generally not greatly affect your health and well-being. While it is best to

maintain a regular sleep cycle, if you are deprived of sleep for a night or two, there is a phenomenon termed “REM rebound”, in which a higher percentage of the most essential REM sleep occurs on nights following such sleep deprivation.

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.

Jeff Feldman, PhD, is the Director of Occupational Rehab Services at Wake Forest University Baptist Medical Center in Winston-Salem, NC.





The Quilt on Tour

Please note: This schedule is subject to change. Call the National Donor Family Council at 800-622-9010 for the most up-to-date information. The entire quilt is not on display at these events, and not all events are open to the public. Please call contact for more information.

June 30	Indianapolis, IN, National Kidney Foundation, <i>Annual Meeting</i> , Marilyn Winn, (317) 722-5640
July 21 - July 25	Washington, DC, National Kidney Foundation, <i>National Donor Recognition Ceremony</i> , Marilyn Jones, (212) 889-2210
August 6 - August 7	Oklahoma City, OK, LifeShare Transplant Donor Services, <i>Donor Family Recognition Ceremony</i> , Julie Avants, (405) 840-5680
September 17	Louisville, KY, National Kidney Foundation of Kentucky, <i>Kidney Walk</i> , Lisa Allgood, (502) 585-5433
September 17	Marion, IN, National Kidney Foundation of Indiana, <i>Marion Kidney Walk</i> , Marilyn Winn, (317) 722-5640
September 24	Newcastle, WA, Northwest Lions Eye Bank, <i>Donor Family Recognition Ceremony</i> , Lois Parker, (206) 686-8500
October 22 - October 23	Pawcatuck, CT, Ninigret Quilters, <i>Pieceful Expressions</i> , Rose Koretski, 860-599-5644

* One panel of the National Donor Family Quilt is displayed year-round at the National Donor Memorial in Richmond, VA. (This Quilt panel will sometimes be moved for display at other national events.) For more information, contact Marilyn Jones at 800-622-9010.

The mission of the National Donor Family Council is to enhance the sensitivity and effectiveness of the organ and tissue recovery process, to provide opportunities for families to grieve and grow and to utilize the unique perspective and experiences of these families to increase organ and tissue donation.



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It costs 37 cents if you forget.