



Ten healing rights of grieving children

By Alan D. Woflelt, PhD

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Author's note: This "bill of rights" is intended to empower grieving children to help themselves heal as well as help direct the adults in their lives to be supportive.

Someone you love has died. You probably are having many hurtful and scary thoughts and feelings right now. Together those thoughts and feelings are called grief, which is a normal (though really hard) thing everyone goes through after someone they love has died.

The following 10 rights will help you understand your grief and eventually feel better about life again. Use the ideas that make sense to you. Post this list on your refrigerator or on your bedroom door or wall. Reading it often will help you stay on track as you heal from your loss. You might also ask the grown-ups in your life to read this list so they will remember to help you in the best way they can.

1. **I have the right to have my own unique feelings about the death.** I may feel scared or relieved. I may feel numb or sometimes not anything at all. No one will feel exactly like I do.
2. **I have the right to talk about my grief whenever I feel like talking.** When I need to talk, I will find someone who will listen to me and love me. When I don't want to talk about it, that's OK, too.
3. **I have the right to show my feelings of grief in my own way.** When kids are hurting, some like to play so they'll feel better for awhile. I can play and laugh, too. I might also get mad and scream. This does not mean I am bad, it just means I have scary feelings that I need help with.
4. **I have the right to need other people to help me with my grief, especially grown-ups who care about me.** Mostly I need them to pay attention to what I am feeling and saying and to love me no matter what.
5. **I have the right to get upset about normal, everyday problems.** I might feel grumpy and have trouble getting along with others sometimes.
6. **I have the right to have "grief bursts."** Grief bursts are sudden, unexpected feelings of sadness that just hit me sometimes even long after the death. These feelings can be very strong and even scary. When this happens, I might feel afraid to be alone.
7. **I have the right to use my beliefs about God to help me deal with my feelings of grief.** Praying might make me feel better and somehow closer to the person who died.
8. **I have the right to try to figure out why the person I loved died.** But it's OK if I don't find an answer. Questions about life and death are the hardest questions in the world.
9. **I have the right to think and talk about my memories of the person who died.** Sometimes those memories will be happy and sometimes they will be sad. Either way, these memories help keep alive my love for the person who died.
10. **I have the right to feel my grief and, over time, to heal.** I'll go on to live a happy life, but the life and death of the person who died always will be a part of me. I'll always miss this special person.

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Make sure your child care provider follows best practices

On August 30, 2001, Wisconsin passed a law requiring certified and licensed child care providers caring for infants less than 1 year of age to receive the most current medically-accepted methods of training to prevent SIDS. A training program was developed and provided statewide through a collaborative effort between the Infant Death Center of Wisconsin (IDCW), Wisconsin Department of Health and Family Services – Bureau of Regulation and Licensing, Wisconsin Department of Workforce Development, area technical colleges, and local child care resources and referral agencies. Last year, the Infant Death Center trained 1,973 child care providers during 53 training programs.

Technical schools now have incorporated the curriculum into new child care provider education. Unfortunately there

are individuals who provide child care in their homes who are neither licensed nor certified. There is no way to ensure these individuals are aware of or practice the safe sleep recommendations of the Back to Sleep program.

Knowing this, it is recommended that parents discuss the best sleep position for their infant with their physician and share with their child care provider the following best practices:

- Infants are placed on their back to sleep unless another sleep position is identified by their physician.
- Infants are placed on a firm sleep surface in a crib that meets safety standards.
- The sleep environment is free of comforters, thick blankets, pillows, stuffed animals or other objects that may impair the ability to breathe.
- Smoking is not allowed in the home or facility.
- The temperature in the room should be comfortable for an adult.
- Infants' faces are kept uncovered during sleep.
- Consider a onesie sleeper
- Couches, chairs and adult beds should not be used as sleeping areas for infants.

When meeting with your child's provider, emphasize the importance of these practices. Do not be afraid to put this in writing for your child care provider.

For more information, visit the following Web sites:

www.cpsc.gov

www.idcw.org

www.nichd.nih.gov/sids ❖

Have you visited our Web site lately?

We are constantly working to improve the Infant Death Center of Wisconsin Web site. Check it out at www.idcw.org.

The Web site has been developed to be a tool for parents, care givers and those supporting bereaved families. Currently, we are working on a new look. We hope you find it helpful and welcome your feedback.

Coming soon ... Wisconsin Perspectives online. Watch for it this spring. ❖

Pick 'n Save WE CARE program benefits IDCW

When shopping at Pick 'n Save, use your grocery purchases to benefit the Infant Death Center. Each time you shop at Pick 'n Save and use your Advantage Plus Savers Card, a percentage of total WE CARE dollars spent will be donated back to the non-profit organization you select.

To sign up, go to the customer service counter at your local Pick 'n Save and ask to sign up for the WE CARE program. Select Children's Hospital of Wisconsin - Milwaukee or organization #110625.

The WE CARE program allows non-profit organizations the opportunity to raise additional funds. The program is available at participating Wisconsin Pick 'n Save stores. ❖

By Ralph A. Franciosi, MD – *Franciosi is a pathologist at Children's Hospital of Wisconsin and a professor of Pathology and Laboratory Medicine at the Medical College of Wisconsin.*

Preventing botulism in infants

As the trend toward more natural baby foods increases, it is important to remember that honey is not recommended for infants. In addition, all fresh fruits and vegetables must be washed carefully before being processed for infant foods. Honey and fruits can contain spores that can cause botulism.

Infant botulism may occur when an infant swallows spores of clostridium botulinum, bacteria that can grow and produce a toxin in honey, soil or dirt.

Unlike in adults, the digestive system of an infant is not able to withstand the presence of the botulinum toxin. In the early 1980s botulism was implicated in cases of sudden and unexplained deaths. Recent reports of infant botulism in New York have brought new attention to this potentially life-threatening disease.

Botulism should be suspected if an infant has the following symptoms: constipation, weak cry, poor feeding

and progressive weakness. If botulism is suspected, a specific test can be done to confirm the diagnosis. The four cases in New York were investigated. None of the infants ingested honey. The cause of the clostridium was not determined. All four patients recovered uneventfully after treatment.

Source: New York City, 2001-2002. MMWR 2003;52: 21-24

Tobacco smoke can be deadly to unborn babies

Smoking during pregnancy is the cause of more than 1,000 infant deaths each year and is the largest preventable cause of low birth weight and premature babies. In 1996, the costs for neonatal expenses due to maternal smoking were estimated at \$366 million nationwide. Second-hand smoke exposure also has been linked to health problems in children including asthma and respiratory illnesses.

Nicotine has a noxious effect on the fetal nervous system. A study of infants between 8 and 12 weeks of age who had been exposed to tobacco smoke in utero showed that these infants slept soundly and were less arousable leading to SIDS.

However, a study by the Center for Disease Control and Prevention

(CDC) claims that pregnant women who want to quit smoking are not getting the support they need due to the high cost of smoking cessation services and treatment. Our goal is to assist families in accessing services that will help them quit smoking and help us reach the goal of healthier babies in Wisconsin.

The following are some resources available in Wisconsin:

American Lung Association

Call Center: (800) 548-8252

Web page: www.lungusa.org/tobacco/

The Wisconsin Quit Line:
(877) 270-STOP

First Breath: (800) 448-5148 or
www.wwhs.org

To access a report on smoking and pregnancy:

Wisconsin Center for Tobacco
Research and Education:
www.ctri.wisc.edu

Wisconsin Tobacco Control Board:
www.wtcb.state.wi.us

Information for health care providers:

www.surgeongeneral.gov/tobacco
The UW Center for Tobacco Research
and Intervention: (414) 227-4507.

Source: Annual Smoking-Attributable Mortality, Years of Potential Life Lost, and Economic Costs-United States 1995-1999

Grief and marriage

By Deborah R. Gemmill

Printed with permission from Getting Through Grief—From a Parent's Point of View

In the period of time between Mother's and Father's Days, I am thrown back in time. It was during these same few weeks that John and I suddenly became bereaved parents. On Mother's Day I happily opened gifts from two children; on Father's Day John sadly opened just one. Each Father's Day since has been a reminder to me of just how different Ty's death affected each of us.

It's so easy for people to make flat statements about other people's grief.

If they really love each other, they can get through this.

If their marriage falls apart, there was something wrong with it to start with.

Something like this can really make or break a marriage.

The feeling was that this was somehow a test of our love – if we survived, then we won. If we didn't ...? We had lost enough already.

As you have undoubtedly realized, everyone must bear his own pain. It's just not true that you can share it – wouldn't we all give it away if we could? I didn't know that then, and what I wanted most was to share my pain with John, and to take some from his aching heart. What we learned was that grief was not necessarily a bonding experience. This is a shocking disappointment to realize when you are reaching with desperate fingers from opposite ends of a sinking lifeboat.

I had expected John to be his usual tower of strength. He had expected me to be my usual organized self, and to take care of details, and to put this in order and move on. Under the weight of our individual sorrow, we failed miserably at these roles we had, up until then,

successfully filled.

What we both needed was to grieve – freely, fully, with no restrictions. It was too hard to do with each other; it was like looking into a mirror. Instead of finding comfort, we only saw our pain reflected.

A large part of the problem was that we were suddenly forced to deal with a situation for which we had no preparation. Like many SIDS parents, this was our first mutual experience with the death of an oh-so-loved one. I didn't have a clue what to do for him. He was equally at a loss. And that seemed to make a very bad situation much worse.

It was too hard to grieve with each other; it was like looking into a mirror. Instead of finding comfort, we only saw our pain reflected.

We were lucky to have family and friends to lean on. It was easier for me than for John. While I had friends I could cry with, his friends, like many men, weren't comfortable with tears or painful reminiscing. I still cringe when I recall what one of John's closest friends said, in the way of a compliment, "At least you didn't make the rest of us feel bad." That, unfortunately, sums up what makes it so hard for any two people to grieve together, but especially parents – we don't want to make the other person feel bad.

The most helpful thing for our marriage was the availability of a support group. John, as he openly admitted, went only because I asked him to, but

there he learned things that helped him understand my grief. He heard other mothers describe their aching arms, and he saw that I wasn't going crazy – I was grieving in a fairly usual way.

I learned the same sorts of things about his grief. I saw how much harder it was for the dads to express their pain. And I listened to other moms talk about their partners who weren't at the meeting, how they grieved in a solitary way, how they didn't want to talk about it, how they just grieved differently. It helped so much to know that, once again, in a different way, we were not alone.

I think the key word is "different." I don't think it's unusual, in those first terrible waves of sorrow, to wonder who hurts the most – mom or dad, but soon the question gives way to reality. Grief is not a contest and pain cannot be compared.

Whatever your beliefs about the difference between men and women, it seems pretty safe to say that we do grieve differently. Respect the difference and seek out what you need from various sources to help you through your personal pain – family, friends, other bereaved parents – all can provide a bridge for you to cross over.

Our marriage survived our grief and we both now believe that it was strengthened as a result. I believe the strength came largely from the realization of our differences and the acceptance of them. It was not an easy road to travel, but how glad we were when we came to the end of it and found that we were together.

We'd lost enough already. ❖

“Our precious child” spring family conference April 25 and 26 – Merrimac, Wis.

The spring family bereavement conference, “Our Precious Child,” will be April 25 and 26 at Devils Head Resort and Conference Center in Merrimac, Wis.

The planning committee includes parents from throughout the state.

Features include:

- Keynote speaker: Debbie Gemmill, bereaved parent, has presented at local, national and international conferences on issues of grief and loss. She is published in periodicals and books on grief and loss, and has presented at bereavement conferences and workshops.
- A chance to meet other families who are dealing with similar situations.
- Memorial program.
- Breakout sessions that provide an open forum for discussions.
- A program for adolescents: a chance for adolescents (age 10 and older) to share their grief if they choose.
- On-site child care.
- Free time: the planning committee

encourages each person to take some quiet time during the conference to reflect, release stress and rejuvenate.

- Reduced-room rates at Devils Head Resort and Conference Center (\$59 per night).
- Campgrounds available at Devils Lake State Park for those who want to camp.
- Local attractions including Circus World Museum in Baraboo, Merrimac Ferry, Devils Lake State Park and the Crane Foundation.

Mission: The conference is intended to help families develop the skills to integrate the death of their infant into their lives. A number of alternatives are available to assist individuals and families in networking and developing their coping skills. You are encouraged to take a break, take time for yourself, think, release stress or just relax.

Opportunity for consultation: Medical director, Ralph Franciosi, MD, will be

available to meet with families by appointment to discuss questions and concerns. If interested, call the central office at (414) 266-2743 for an appointment and/or further information.

Cost: Adults \$15 each. Fee includes continental breakfast, lunch and conference. Children \$5 each for materials and child care.

More about the speaker: Debbie Gemmill is a bereaved parent whose son, Tyler, died in 1982. She addresses grief as a personal challenge that each person faces in their own individual way. She has shared her family’s story with other bereaved parents through published works and presentations. See the article by her on page 4.

More information: A mailing will be sent out, however, please feel free to call for more information. If you do not receive the mailing by March 25, use the form below to let the committee know you are interested in attending.

Agenda

Friday, April 25

7 p.m to 9 p.m. Registration

Memorial Quilt: On Friday evening, families can create a fabric square in remembrance of their baby. Fabric and supplies will be provided. You only need to bring your ideas.

Saturday, April 26

8 a.m. Registration

8:30 a.m. Opening

8:50 a.m. Keynote address

10 a.m. Break

10:15 a.m. Memorial program

11:30 a.m. Lunch

12:45 p.m. Candle lighting ceremony

1:15 p.m.

Breakout sessions:
Writing to express your grief
Men’s grief
Women’s grief
What to tell other children

2:15 p.m.

Break

2:30 p.m.

Breakout sessions:
Subsequent pregnancy
Intimacy/relationships/couples
Couples’ grief
Grief in the workplace
Closing with bubble release

3:30 p.m.

I wish to register for the conference:

Name: _____

Address: _____

Number of adults attending: _____

Number of children: _____

I will be using child care:

___yes ___no

Send to:

Infant Death Center of Wisconsin
PO Box 1997
Milwaukee, WI 53201-1997

Center and satellite summaries

U P D A T E

Infant Death Center and South/ Southeastern Region

Anne Harvieux: (414) 266-2746 or

Larry Uglow: (414) 266-2745

Educational programs

Presentations on SIDS, risk reduction strategies, grief/loss issues and services provided by the Infant Death Center of Wisconsin were given on:

Dec. 19 – Milwaukee County Paramedic training.

Feb. 13 – Wisconsin Child Care administrators.

Upcoming programs

March 15 – Association of SIDS and Infant Mortality Programs.

April 14 – Wisconsin Association for Perinatal Care, Madison.

April 29 – Concordia University Risk Reduction.

Programs for families

A support group for families meets at 7 p.m. every fourth Tuesday of the month at Children's Hospital of Wisconsin. For more information call Larry Uglow, (414) 266-2745.

Other

Nov. 15 – Statewide Council meeting, Madison.

Dec. 19 – Regional Council meeting, Milwaukee.

Collaborations

The center continues to be involved with:

- 4Cs of Milwaukee County.
- Association of SIDS and Infant Mortality Program Professionals.
- Dane County Pediatric Death Review.
- Fetal Concerns Program.
- Great Lakes Intertribal Council Honoring our Children Project.
- La Causa.
- March of Dimes.
- Milwaukee Fetal Infant Mortality

Review Project.

- Milwaukee Healthy Beginnings Steering Committee, Data Evaluation Committee and Consortium.
- Milwaukee Tobacco Free Task Force.
- State of Wisconsin Bureau of Health Information.
- State of Wisconsin Division of Public Health.
- Supporting First Time Parents.
- Wisconsin Association for Perinatal Care.
- Wisconsin Child Care Resource and Referral Network.
- Wisconsin Early Childhood Association.
- Wisconsin Maternal and Child Health Coalition.
- Wisconsin Public Health Association.

Western Region

Phillip Nielsen: (608) 791-9410

Educational programs

Presentations on SIDS, risk reduction strategies, grief/loss issues and services provided by the Infant Death Center of Wisconsin were given on:

Nov. 14 – Fort McCoy child care providers.

Nov. 16 – A children's grief workshop "Grief Through The Eyes of a Child: Handling the Holidays."

Nov. 19 – Presentation to parish parent group, Mary Mother of the Church, La Crosse.

Other

Dec. 19 – Annual La Crosse pregnancy loss and infant support group Christmas memorial program.

Programs for families

The La Crosse Pregnancy and Infant Loss Support Group meets every third Wednesday from 7 p.m. to 8:30 p.m. Please call (608) 791-9410 for more information or to register.

A Children's Grief Workshop is being planned for Spring. Call for more details.

Northeastern Region

Beth Tourville: (920) 969-7903

Upcoming events

Oct. 19 – 2nd Annual Walk to Remember, Appleton – a memorial walk and tree planting at Bubolz Nature Preserve is open to anyone who has experienced a miscarriage, stillbirth or infant loss. No registration necessary. Call (920) 969-7903 for more information.

Programs for families

Remembering Through Sharing support group meets the first Wednesday of the month at 7 p.m. No registration is necessary. Call (920) 729-2087 for meeting location and information.

Northern Region

Dora Gorski: (715) 843-1877

Educational programs

Presentations on SIDS, risk reduction strategies, grief/loss issues and services provided by the Infant Death Center of Wisconsin were given on:

Dec. 2 – Health Fair at Cedar Creek Mall, Rothschild.

Dec. 9 – Memorial Program, Antigo.

Dec. 12 – Memorial Program, Wausau.

Feb. 3 – Educational presentation to mothers in the W2 program at Children's Service Society in Wausau.

Programs for families

SAID (Support After Infant Death) meets on the second Thursday of every month at 7p.m. at 705 S. 24th Ave. Suite 402 in Wausau. For more information call Dora Gorski (715) 843-1877.

Other

Nov. 11 – Northern Regional Community Council Meeting, Wausau.

Dec. 6 – Great Lakes Inter-Tribal Advisory Council Meeting, Lac du Flambeau.

Thank you to the families who have shared with me their birthday memorial celebrations. (See the Nov. 2002 edition of

Center summaries cont.

Wisconsin Perspectives) If you still have ideas to share, please send via mail or E-mail to:

Dora Gorski
705 S. 24th Ave., Suite 402

Wausau, WI 54401

Dora.gorski@cssw.org.

There also will be a display and an opportunity for more sharing at the spring family conference.

The Infant Death Center thanks the following individuals for their generous donations in honor of someone or in memory of a special child.

These donations were received between
Oct. 1, 2002 and Jan. 30, 2003.

In honor of
Dr. Michael F. Gutzeit

Mr. & Mrs. Donald J. Feurt

Ms. Cathy J. Livingston

Mr. & Mrs. Brian E. Livingston

In memory of
Alex Amundson

Mr. & Mrs. Richard P. Larsen

Lauren Anheuser

Mr. Gerald Race

Ron Barnes

Mr. & Mrs. Richard P. Larsen

Erik Baumler

Mr. & Mrs. Richard Baumler
Mr. & Mrs. Douglas Bodden
Mr. & Mrs. Michael Petrusich

David Joseph Crawford

Mr. & Mrs. Perry Crawford

Danielle Marie Fischer

Mr. & Mrs. Jason C. Fischer

Celine Elizabeth Groves

Mr. & Mrs. Simon J. Neicheril

Kera Jo Haase

Mr. & Mrs. Kevin R. Colwell & Family

Patrick Harrington

Rev. & Mrs. James L. Harrington

Ellen Marie Hoffmann

Mr. & Mrs. Warren L. Wilson

Nancy Kellam

Mr. James L. Kellam & Family

Madeline R. Thorpe

Mr. & Mrs. Daniel N. Burnside

Cassidy Tiana Weyek

Mr. & Mrs. James A. Weyek

Upcoming Events

The following families are planning upcoming events. We encourage you to save the date and support their efforts to provide financial support for the center:

March 1, 2003 – 2nd annual volleyball and dart tournament in memory of James Lucht

The event will be held at:
Royal Sports Center
2401 Cedar Drive,
Plover, Wis.

For more information call Lisa and Herbert Lucht at (715) 341-8950.

June 30, 2003 – 9th annual Jay Hashek Golf Outing

The event will be held at:
Tuckaway Country Club
Franklin, Wis.

For more information or to register call (414) 525-8211.

Aug. 11, 2003 – 5th annual Beno golf outing

The event will be held at:
Twin Oaks Golf Course
Denmark, Wis.

For more information call (920) 490-5130.

Aug. 19, 2003 – Shane Locke Hasbrook Memorial Golf Outing

The event will be held at:
Silver Spring Country Club
Milwaukee, Wis.

For more information call (262) 628-2833.

Fundraising kits now available

Many families consider fund raising for the Infant Death Center, but do not always know where to start. Children's Hospital Foundation, in collaboration with center staff, have developed a folder with information that can help you decide, plan and promote an event.

If you are considering a fund-raiser to benefit the Infant Death Center and would like a kit, call Laura Fish at (414) 266-6197.

Wisconsin Perspectives is the newsletter of the Infant Death Center of Wisconsin. The goal of this newsletter is to promote the statewide exchange of information regarding infant death issues.

The Infant Death Center of Wisconsin is funded by Children's Hospital of Wisconsin and a MCH Title V Services Block Grant, through the Maternal Child Health Bureau of the Health Resources and Services Administration, Department of Health and Human Services.

If you are receiving this newsletter for the first time, it is because you have been referred to the center at Children's Hospital of Wisconsin. Please contact us at (414) 266-2743 if you wish to be removed from the mailing list. With any questions or comments about the program or newsletter, contact Anne Harvieux, program administrator, at (414) 266-2746 or aharvieux@chw.org.

To reach the center and the South/Southeastern regional office, contact Anne Harvieux at (414) 266-2746 or aharvieux@chw.org, or Larry Uglow at (414) 266-2745 or luglow@chw.org. To reach the satellite center in your region, contact Phillip Nielsen in Western Wisconsin at (608) 791-9410 or Nielsen.Phillip@mayo.edu, Dora Gorski in Northern Wisconsin at (715) 843-1877 or Dora.gorski@cssw.org, or Beth Tourville in Northeastern Wisconsin at (920) 969-7903 or Btourville@chw.org.



Children's Hospital of Wisconsin, Inc.
PO Box 1997
Milwaukee, WI 53201-0997

New arrivals:

Congratulations to the following families on their new additions:



Hannah Kelby Bagneski was born Oct. 8 to Bill and Kelly Bagneski.

Lily Olivia Leseur was born Oct. 22 to Gail and John Leseur.

Jalyn Chance Hackney was born Oct. 29 to Kila and David Hackney.



Sarah Burkee was born Nov. 2 to Jeannette and Paul Burkee.

McKenna Rose Casper was born Dec. 27 to Nancy and Wayne Casper.



Grace Lynn Renz was born Jan. 29 to Amy and Greg Renz.

Natalia Evelyn Voegeli was born Feb. 15 to Penny and Phelan Voegeli.

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