

WISCONSIN PERSPECTIVES

**HOW TO HELP YOURSELF AND OTHERS
WHEN LOSS IS NO LONGER NEW**

By Debbie Gemmill

A few months after our son Tyler died from SIDS, a well-meaning neighbor bent down to 4-year-old Jennifer’s eye level and asked, “Well, are you feeling better about your brother?” And with 4-year-old wisdom and candor, Jennifer replied, “Nope. He’s still dead.”

As the mother of a baby who died 16 years ago, I might offer the same reply today. Even though time has softened the jagged edges of grief, my son still is gone. In examining my own feelings about a loss that is no longer new, I questioned if I was alone in wondering what has been the effect of my son’s death on me and on my family, years later.

When grief is new, it is overwhelming. It invades every part of our lives and refuses to be ignored. Thank goodness it is true that time helps, and even heals a great deal, but it doesn’t erase the fact that a child lived and died. In my many discussions and correspondence with SIDS families whose loss has been five, 10, 20 or more years ago, this is clear – no matter how long it’s been, we don’t forget. We may not think of our child every day, but we remember. And we would really like it if others would remember, too.

“After the first birthday and anniversary, no one called,” a mother shared with me. “I felt I was the only one who remembered she had lived. Do we get to remember for only one year?” Many parents realize the responsibility for remembering seems to rest on their shoulders, and they have come up with touching, creative ways to honor their child’s memory. Candlelighting, tree planting, balloon releasing, kite flying – all are tangible ways to say, “I remember you.” Other families donate to medical research or to charities of their choice in their babies’ names. For Tyler’s 17th birthday, our family donated a children’s book to our local library. It’s not much, but it helps us remember that his brief life mattered, and it makes us feel good to know other living children will pick up this book and enjoy it.

Although my grief is no longer new, I find it sometimes comes back with strength that surprises me. My ears still perk up and my heart still races each time I hear a newsflash about SIDS, each time I pick up the paper and see a too-small headline briefly describing the latest research theory. I’ve been involved long enough within the SIDS community to realize that theories come and go, but I’m still an optimist, and my heart still plummets when I reach the end of the broadcast or article and realize we’ve not yet solved the mystery.

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JASON JARZEMBOWSKI, MD, PHD

STUDY REVIEWING THE IMPACT OF INFECTIONS ON UNEXPECTED INFANT DEATHS INCONCLUSIVE: Comment on "Infection and sudden unexpected death in infancy: a systematic retrospective case review." (Weber MA, et al. *Lancet* 2008;371:1848-1853).

By Jason Jarzembowski, MD, PhD – Dr. Jarzembowski is a pediatric pathologist at Children's Hospital of Wisconsin, an assistant professor of Pathology at Medical College of Wisconsin and medical adviser for Infant Death Center of Wisconsin.

The authors of this article are affiliated with the Great Ormond Street Hospital for Children and with the Institute for Child Health, both well-respected institutions in London. In the United Kingdom, the coroner's office and national health care system are structured such that infant autopsies from a large area of southern England are performed by pediatric pathologists at this hospital. (Here in Wisconsin, these cases typically would be distributed among the medical examiners' offices of the various counties.) This centralization allowed the opportunity to review all 1,516 infants autopsied during a 10-year period; of these, 546 were considered "sudden and unexpected."

Autopsies identified a bacterial infection in 56 of the infants and a noninfectious cause of death (undiagnosed congenital anomalies, for example) in another 72 infants. They also excluded 39 cases of probable viral infection or known secondary bacterial infection following initial collapse and resuscitation. This left 379 cases of "sudden unexplained death in infancy." It is important to note that this SUDI category does not rely on scene investigation and does not take into account the circumstances of death with regard to co-sleeping or the position in which the infant was found, so the study group does not equate to sudden infant death syndrome, a diagnosis that requires evaluation of these factors. In essence, their group includes SIDS along with other cases.

After classifying the cases, researchers looked at the results of microbiologic cultures performed at the time of each autopsy and excluded cultures that were positive for non-pathogenic bacteria (contaminants, normal bacteria inhabiting the body, etc.). They then compared the results from explained noninfectious deaths and SUDI deaths and found more positive cultures in the latter (19 percent versus 11 percent). This also was true looking just at organisms known to cause sepsis and disseminated infection. Thus, the authors report a correlation between infection and SUDI, and they propose that these bacteria may contribute to development of conditions leading to SUDI and SIDS.

These results are intriguing but show only correlation, not causation, and must be interpreted in the correct context. First, more than 70 percent of all autopsy cases yielded positive cultures (an astonishingly high rate), and the negative rate was identical across all patient groups. Postmortem cultures always are subject to high false-positive rates, as organisms quickly begin to proliferate after death, and even pathogenic species are everywhere in nature with no symptoms in many people. Second, there was no microscopic evidence of infection in these patients (or else the death would have been "explained"), so the significance of positive cultures is unclear. The bacteria perhaps might be secreting toxins or indirectly affecting the infant in other ways without causing classic infec-

tion. Breastfeeding, thought by some to exert a protective effect against SIDS, might do so by bolstering an immature immune system with maternal antibodies against infection. Third, it would be useful to look exclusively at well-defined SIDS cases instead of the more widely-encompassing SUDI to see if the trends are maintained. To date, there is no mechanistic evidence for bacteria causing or directly contributing to SIDS, and the best hypothesis is still that SIDS is a multifactorial process predisposing certain infants to a fatal event that can be triggered by a variety of risk factors (positioning, smoking exposure or even subclinical infection) alone or in concert.

So what does this all mean for parents and caregivers? The findings should generate interest, but not any significant practice changes. Parents and caregivers should continue to use proper positioning, safe sleep environments and smoking cessation around infants. These clearly are the most beneficial, evidence-based steps to be taken to reduce the incidence of SIDS. Infants younger than 3 months old should be promptly evaluated for any cold or flu-like symptoms by their pediatricians (and not given cold or cough medicine unless specifically prescribed by their doctors). And finally, while research into this potential link continues, cultures should become part of the standard workup of all SUDI/SIDS deaths to facilitate research into this tragic and still unexplained phenomenon. ↩

| PERSONAL VIEWPOINT

HOW TO HELP

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I don't think I'm alone as I revisit the "if onlys, what ifs, I should have" that new risk-reduction information brings up. And yes, of course, I am grateful and supportive of ongoing research efforts, and I do know I did the best I knew to do with my son, but still ...

Other milestones can trigger those memories of pain. Wonderfully happy events such as family birthdays, graduations, weddings and births often bring tears of joy, but for some of us, the tears sting as we look with love at the celebration and realize one important person is missing. As the years go by, we rarely will mention his or her name at these happy occasions, but please be sure that although we are delighted and relieved that life does, indeed, go on, we still miss our child. We still see the empty chair.

One of the hardest parts about being a "seasoned griever" (as someone in our Years Later session described us) is that there are so few people with whom to talk about our child. As the years pass, there are fewer opportunities to just reminisce. One father had this

to say, "Everyone in my family still talks about my grandfather who died at 80. No one thinks it's unusual to say his name and to talk about our memories of him. And yet it feels somehow strange for us to bring up the few memories we have of our son, especially now that it has been so many years."

It has been so many years, but it still hurts. Not the agonizing, blinding pain of the early days, but sort of a soft ache, with occasional deep pangs of grief. We always will be the parents of a child who died; our family always will be missing an important member. It is impossible to realize the many ways in which the loss of a child continues to impact our lives. Perhaps it is enough to accept that it has forever changed us, for better or for worse. We understand that death is a part of life and that acknowledging our losses is a necessary part of living and moving on. And we are, but we are carrying our memories with us. ↵

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| PERSONAL VIEWPOINT

PUZZLE PIECE

By Shannan Evans

I see it in you.

I feel it in me.

The lost look;

The picture of no peace.

The display of despair,

As the hurt hangs on.

Anger stays so alert.

Thoughts may get good,

But, feelings take control.

Few seem fair;

Efforts are empty.

So many unconquered questions.

Wasn't this a mistake?

Won't I awake to a remedy?

The answers come unclearly;

Some heard, others hidden by hurt.

Day by day we walk,

With one another in search of

What is gone.

Giving each other support and strength;

Traveling together; Becoming the

Missing peace!

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Did you know that *Wisconsin Perspectives* can be viewed online?

While we have a large number of people on our mailing list that receive this newsletter in print, many families and organizations now choose to receive it electronically. Electronic newsletters save paper and trees, reduce the amount of paper coming into your home or office,

and help reduce our paper, printing and postage costs.

The newsletter can be found on our Web site at www.idcw.org. It is easily accessible from our home page. You also are able to view archived copies of the newsletter online. While you are on the Web site, take some time to browse and see some of the items that have been

added. We welcome suggestions on how the site can better meet your needs.

If you would prefer to receive *Wisconsin Perspectives* electronically, e-mail Connie Haugh at chaugh@chw.org, and we will remove your name from the print mailing list. If you have questions or suggestions, call Anne Harvieux at (414) 266-2746 or e-mail at aharvieux@chw.org. ↵

*Sunsets remind me
to prepare
for tomorrow's possibilities.*

By Diantha Ain

PERSONAL VIEWPOINT



LESSONS IN GRIEF

By Darcie D. Sims, PhD

Every generation seems to have moments that color and distinguish them from every other generation, and Sept. 11, 2001, is one such moment. This date has become one of the defining moments for this generation. Just as many will recall where they were when President John F. Kennedy was assassinated or when Martin Luther King, Jr. was killed or when the Space Shuttle Challenger exploded, each of us will forever recall where we were and what we were doing when the events of Sept. 11, 2001, began to unfold and our lives changed forever.

We now label that day as an anniversary; a strange term used both to mark a celebration of a marriage and the passing of years following a death. Sept. 11 now has entered the history books as a defining moment in American history, indeed the history of the world. So perhaps it is appropriate to take a few moments to reflect upon our changed landscape and see if we can understand what has changed in the weeks and months since that horrible of horrible days began.

At first, a sense of disbelief overwhelmed us, and no one could imagine the reality we were forced to grasp instantly. Disbelief quickly turned to horror and horror into a trauma so deep that it has taken months just to be able to scratch the surface of the hurt.

We watched in horrified fascination as events unfolded and even now, it still is difficult to imagine such scenes. The debris has been cleared away and, on the surface at least, life has returned to its frantic pace. There are some changes we all have experienced as we have struggled to make sense out of what has happened to ensure our continued safety. These changes reflect a changed attitude and response to a loss of inno-

cence and trust. We grieve as a nation as well as individuals.

What is it in this national grief and during the season of its anniversary that we can say we have learned from struggling through the valley of the shadow of grief? Are there any lessons to be learned, gifts to be received, nuggets of truth to be savored? Can we salvage something from the tattered remains of our former selves and life? Can we sift through the wreckage and find some slivers of hope that will help us reweave the fabric so torn by the deaths of those we love? What is hope, and can we find it in the midst of despair?

Lesson 1 – Change in perspective

What's important now? It seems as if I have a new perspective on life. I am no longer worried about the length of the grass or coordinating my outfit. The price of lettuce no longer sends me into orbit, nor does the absence of my favorite ice cream flavor. I seem to measure time differently as well. I don't want to waste my time in lines or waiting until I lose a few pounds or until I get wiser. I want to live now, and the only time I have is for those I truly cherish. I don't want to spend time on the phone with advertisers or listen to elevator music while I'm on hold because my call is important to someone. I have a new sense of perspective, and I am more comfortable with living in the now than ever before. I have learned it is all any of us really have.

Lesson 2 – Don't get stuck on the small

I no longer want to carry guilt or regret. I do not have time for those feelings that only rob me of energy. I don't want to get stuck in traffic, be caught worrying about my to-do list or trying to remember schedules. I'll write everything down and then secure it to the refrigerator

with a magnet. I want to stop doing so much and just be.

Lesson 3 – Embrace your pain

We have learned there are no magic wands or special words to say that will erase the hurt and pain of being bereaved. I will no longer ignore or postpone the work of grief. There isn't enough time to let grief dictate my days and hours. I will simply embrace whatever I am feeling and work through it. I no longer will allow guilt or hurt or sadness to overwhelm me. I will, however, allow myself the time and space I need to wrestle these feelings to the ground and become victorious in my healing. We don't get over grief. We get through it!

Hurt and pain have their lessons, and we cannot rob ourselves of the richness of the tapestry that hurt and love weave together. To eliminate one from the loom is to break the thread and steal away the fabric. The gifts within love are obvious. We do not dispute them. Yet, the gifts within hurt are equal. I could not understand light if I had not known dark. I could not sing sweet if I had not known bitter. I could not laugh if I had not cried.

Lesson 4 – Look for joy

With so much pain to carry, I have learned that I sometimes need a pair of rose-colored glasses. I do not want my outlook to be influenced only by the sadness and depression of grief. Whatever I see is what I choose to see. I can carry pain and sorrow or I can remember the joy of my loved one's life. I think I like remembering that more than the list



of things I will never know or experience. We must work at finding the joy and when we do, we must let it come back without ruining it with a dose of guilt. Our loved one died, we did not. And I can forgive myself for that and search for the moments we sang and danced together or I can bury myself in the despair that threatens to overwhelm me. The choice is mine. And I choose joy.

Lesson 5 – Don't wait for anything

The death of a loved one teaches us to embrace the moments of our life rather than waste them in search of tomorrow. I used to be one of those efficient people who bought birthday presents all year long and wrapped them and stuck them in a closet, waiting until the right day to give them. Sept. 11 taught me (again) that no one is promised anything except yesterday. There may be no more tomorrows for any of us, and while that may seem pessimistic, I believe it is more honest than sad. It simply means I don't want to wait until some special day to give you a gift! I want to have Christmas and Hanukkah and all of my favorite holidays every day! I'm going to say, "I love you," now instead of waiting. The time to live is now and I'm not going to wait anymore! I do not

know when I will have to learn to live without someone I care about, so I want to say, "I love you," now.

Lesson 6 – Let go of regrets

Why do we spend so much time and grief over not saying good-bye? Why do we wash away the words we did get to say over a lifetime of loving someone with the single lament, "I didn't get to say good-bye?" Why are those words so important that the lack of them creates a lifetime of additional hurt and pain? I did get to say good-bye, and when the moment came, I did not say those words. And if you had had the chance, nor would have you. I said, as you would

have, "I love you." Why would anyone want to say good-bye? It is simply too final, too harsh, too forever.

Surely your loved one knew you loved him or her. Surely your loved one knew you cared. And even if you don't believe he or she knew, you can't do something about that right now. Why let not saying good-bye rob you of the memories of what you did get to say and how you lived your lives together? Why let not saying good-bye steal away the joy of knowing your loved one was in your life and still is a thread in your fabric, to be woven forever around your heart?

We never know when an ordinary day will turn into a day that gets marked down in the family history as a not-so-ordinary day. But all of us can live our lives so we can leave with few regrets. Don't let the events of the past several months rob you of your hope, your passion, your joy in living. Let it become a lesson for all of us to live our lives as if there were only moments left, because that is all there really are anyway.

Moments – just moments, one after another, each special and sacred in their own way, each waiting to be etched forever on our memories or lost in the sea of millions of other ordinary moments. Take advantage of the moments we have and spend them wisely. Spend them saying, "I love you," instead of wishing you had said good-bye.

Lesson 7 – Thanks for the little while

I want to spend my days being grateful for the moments that I did have with my child, my mom, my dad and all of those whom I have loved so dearly. Remember the "gifts" you have received from your loved ones and cherish the moments you shared. Those moments were not enough, but they were something and don't you dare forget them! The lessons we have learned from the events of Sept. 11, and from the personal darkness we have endured, are strong and powerful ones. They were expensive beyond human comprehension, but they are ours to do with as we choose. I choose joy and to remember the life, not dwell in the house of loss forever.

We have learned to define hope in many different ways. For me, hope is not the absence of pain or sorrow or sadness. Hope is the possibility of renewed joy –

the memory of love given and received. Hope is you and me and the person next door, down the street and in your dreams. We are each other's hope. And as we reach out across our own personal darkness to find the other hands searching, we become a miracle. Not a miracle of individual strength, but a testimony to the strength of the human spirit. We have become a family circle, broken by death, but mended by love. *May love be what you remember the most!* ←

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DANCE WITH ME

By Diana Peterson

In the room of golden sun

I wrapped my arms

Around my little one

Holding him close

we danced cheek to cheek

His soft brown eyes

sparkled with a flash

As I grabbed his small precious hand

to glide in the room

"Dance Momma Dance.
I love to dance."

Each sweeping movement

Holding him close

As if to hold on forever

Keep playing the song

And make it last

If only for eternity.

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MARCH 2008 THROUGH AUGUST 2008

EDUCATIONAL PROGRAMS

- Jan. 11 – Wisconsin Early Childhood Conference, Madison.
- March 11 – Fulfilling the Promise, Waukesha, Wis.
- May 2 – Wisconsin Family Child Care Association, Wisconsin Dells, Wis.
- May 28 – Family Resource Center of Sherman Park, Milwaukee
- May 30 – Concordia University Parish Nurse Conference, Mequon, Wis.
- June 4 – Aspirus Baby Fair and Open House, Wausau, Wis.

INFORMATIONAL EXHIBITS

- Jan. 11 – Wisconsin Early Childhood Conference, Madison.
- March 11 – Fulfilling the Promise, Waukesha, Wis.
- April 19 – Latino Health Fair, Beloit, Wis.
- April 19 – Watertown Community Health Fair, Watertown, Wis.
- April 19 – Family Resource Fair, Racine, Wis.
- May 2 – Wisconsin Family Child Care Association, Wisconsin Dells, Wis.
- May 10 – Women of the World, Milwaukee.
- May 17 – Health Care for Kids, Milwaukee.
- May 17 – Through the Generations, Beloit, Wis.
- May 30 – Community Baby Shower, Aspirus Hospital, Wausau, Wis.
- June 24-25 – Women, Infants and Children Conference, Appleton.
- July 23-24 – Wisconsin Public Health Association Meeting, Madison.
- Aug. 19 – Wisconsin Public Health Nurse Association Meeting, Stevens Point.

PROGRAMS FOR FAMILIES

SAID (Support After Infant Death) Group – Second Thursday of each month, Aspirus Hospital, Wausau, Wis.

INITIATIVES INFANT DEATH CENTER OF WISCONSIN IS COLLABORATING WITH AT THIS TIME

- Association of SIDS and Infant Mortality Program Professionals
- Beloit African American Infant Mortality Coalition
- Black Health Coalition of Kenosha
- Black Health Coalition of Wisconsin
- Center for Grieving Children
- Central Wisconsin NICU Transitions Committee
- Cribs programs in Barron County, Bayfield County, Kenosha County, Lincoln County, Marathon County, Milwaukee County, Taylor County and the cities of Neenah and Racine
- Concordia Metcalfe Community Health Improvement Project
- Dane County Child Fatality Review Team
- Fetal Concerns Program
- Fetal Infant Mortality Healthcare Action Team
- Great Lakes Intertribal Council Honoring our Children Project

- Healthy Babies in Wisconsin Steering Committee and Regional Action Teams
- Healthy Native Babies Consortium (Menominee, Stockbridge-Munsee and Ho-Chunk nations)
- Marathon County Child Fatality Review Team
- Marathon County Start Right Program
- Madison Health Department/Prenatal Care Coordination
- Marathon County Healthy Babies
- March of Dimes
- Milwaukee Birthing Project
- Milwaukee County Child Fatality Review Team
- Milwaukee Fetal Infant Mortality Review Project
- Milwaukee Healthy Beginnings
- Northeast Wisconsin Technical College
- Northern Wisconsin NICU Transitions Planning Committee
- Racine County Death Review Team
- Racine Fetal Infant Mortality Review Team
- Racine Infant Mortality Coalition
- Safe Kids Wisconsin
- Spanish Center of Kenosha
- State of Wisconsin Bureau of Health Information
- State of Wisconsin Division of Public Health
- Waukesha County Child Fatality Review Team
- Wisconsin Association for Perinatal Care
- Wisconsin Child Care Resource and Referral Network
- Wisconsin Early Childhood Association
- Wisconsin Public Health Association

OTHER

- March 28-29 – Family Conference, Middleton.
- Feb. 13 and May 14 – Northeastern Regional Community Council Meeting, Neenah.
- March 17 and June 16 – Northern Region Community Council Meeting, Wausau.
- March 26 – Southern/Southeastern Regional Community Council Meeting, Milwaukee.
- April 30 – Western Region Community Council Meeting, Eau Claire.
- July 25 – Statewide Community Council Meeting, Portage.

To make a gift

Children's Hospital and Health System Foundation can assist you if you or your organization would like to donate to the Infant Death Center of Wisconsin. To reach the foundation office, call (414) 266-6100.

Periodically throughout the year, you may receive mailings from the foundation seeking support. Often there is a card enclosed with options for giving. Feel free to check the Infant Death Center as an option, or write in the center if it is not listed on the card.

The center also can be chosen as an option on your United Way designation form. Your support of the program allows us to provide a continuum of services throughout the state.

Many companies provide a match to donations given by their employees. Check with your employer to see if such a program is available to you. ☞

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| IN MEMORY OF

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 Jan. 1, 2008, and May 31, 2008.

Great Grandchild Caine

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INFANT DEATH CENTER WELCOMES NEW MEDICAL ADVISOR

Jason Jarzembowski, MD, PhD, has been named as the new medical adviser for the Infant Death Center of Wisconsin. Dr. Jarzembowski also is a pediatric pathologist at Children's Hospital of Wisconsin and an assistant professor of Pathology at Medical College of Wisconsin.

Dr. Jarzembowski earned his doctorate from the University of Wisconsin-Madison and his medical degree with research honors from the Medical College of Wisconsin, Milwaukee. He was a resident in Anatomic and Clinical Pathology at University of Michigan and then completed a fellowship in Pediatric Pathology at Washington University in St. Louis. He is board certified in Anatomic and Clinical Pathology and holds subspecialty certification in Pediatric Pathology.

Dr. Jarzembowski is especially interested in perinatal pathology, placental pathology and pediatric solid tumors. He supervises a research program studying molecular abnormalities of the pediatric tumor neuroblastoma, for which he was awarded the Young Investigator Research Award by the Society for Pediatric Pathology in 2005. He serves on the editorial board of the journals Archives of Pathology and Laboratory Medicine and Clinical Medicine: Pathology. He is a member of the United States and Canadian Academy of Pathology, the Society for Pediatric Pathology, the College of American Pathologists, the American Society for Clinical Pathology and Sigma Xi. 



WISCONSIN PERSPECTIVES is the newsletter of the Infant Death Center of Wisconsin. The goal of this newsletter is to provide information to help reduce infant deaths and improve infant health.

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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. 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 Vivian Jackson at (414) 266-2745 or vjackson@chw.org. To reach the satellite center in northern/western Wisconsin, contact Dora Gorski at (715) 218-8424 or dora.gorski@cssw.org. To reach the satellite center in northeast Wisconsin, contact Anne Harvieux at (414) 266-2746 or aharvieux@chw.org.

WISCONSIN PERSPECTIVES

NEW ARRIVALS

Congratulations to the following family on their new addition.

Gabriel Grant Ogden was born June 2, 2008, to Georgia and Craig Ogden.

If you would like your baby's birth announcement in the newsletter, contact the Infant Death Center satellite or central offices.



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