

# Healing Quilt Newsletter

Fall 2008



## Healing Quilt 2008 Revisited

by Linda Lehmann, bereavement coordinator

Healing Quilt will be 10 years old in 2009. Over the years, it has provided comfort and support to hundreds of bereaved families. As we look forward to the next decade we pause to reflect on the last nine years.

### History of Healing Quilt

Before Healing Quilt, bereavement support to families had been around for many years, but the care may not have always been consistent. For example, if a child died after having been treated for cancer over a period of years, the family may have felt a strong connection to the hospital, and the hospital staff may have felt a strong connection to the family. This family probably received great bereavement care. However, if a child came into one of the emergency departments and died within 15 minutes, there may not have been a strong connection between the family and the hospital. That family probably did not receive bereavement care.

So a small group of chaplains, social workers, child life specialists, nurses, and others had a vision to bring together in one program the best of what was already being offered. The program was named Healing Quilt.

The quilt, a symbol of comfort, represents many pieces that make up the whole. The vision of Healing Quilt was to offer families a number of services to participate in. Starting a new program meant that the hospital needed someone whose only job was to focus on the program. I was hired as the first bereavement coordinator for the program in the year 2000. My role was to ensure that the program offered consistent care and to help to develop program services to carry out its mission.

The seed money for Healing Quilt came from an employee giving campaign, and in 1999 it was launched with limited programming. Today, Healing Quilt has grown into a comprehensive bereavement support program that offers families a wide assortment of programs to choose from. The program relies on staff from chaplaincy, child life, and social work to help carry out its mission. Recently, bereaved parents whose child died more than two years ago began to help with programming.

### Healing Quilt programs

**Bereavement follow-up:** Grief packets are given at the time of death. Year anniversary and birthday remembrance cards are sent to families the year following their child's death. Other forms of support include deferring billing, canceling future doctor and clinic appointments of children who have died, informing parents of the status of autopsies.

**Memorial services:** A perinatal loss memorial service is held in October and a memorial service for bereaved parents is held in May.

**Grief support program:** Groups are held twice a year in the fall and spring. Groups offered include daytime grief group, groups for children ages 3 to 18, bereaved parent groups specific to specific losses.

**Parent to Parent:** Bereaved parents whose child died more than 2 years ago offer support to newly bereaved parents.

**Retreats:** Overnight retreats for bereaved moms and dads.

**Camp Connect:** A weekend retreat for bereaved siblings.

**Healing Quilt newsletter:** Sent out twice a year.

*Healing Quilt 2008 Revisited, continued on page 6*

### Inside this issue

Healing Quilt depends on the generosity of others to support its many services.....	2
How to be your grieving child's best advocate in school .....	4 and 5
Grief guides.....	5
Remembering Andrew: My grief through the years....	6
Calender of events .....	7



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## Healing Quilt depends on the generosity of others to support its many services

### We gratefully thank the following individuals and companies for their financial support:

Andrew and Courtney O'Brien  
 Brent and Lisa Mellum  
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### We gratefully thank these individuals for helping us offer these programs:

#### Spring Grief Groups

Brian Brooks, Jenny Cook, Janet Farmer Theresa Huntley, Linda Lehmann, Dee Moore, Lori Olson, Kara Pittman, Heather Prudden, Christina Ufer-Kane, Carin Willette, Joan Ward

#### Perinatal Loss Group

Brian Brooks , Annette Klein

#### Grandparent Gathering

Theresa Huntley, Linda Lehmann

#### Rainbows of Reflection Memorial Service

*Staff:* Sherry Braun, Brian Brooks, Cyndee Daughtry, Abby Davis, Diane Dingley, Carol Faust, Dr. Alan Goldbloom, Jennifer Johnson, Joy Johnson-Lind, Linda Lehmann, Caron Moore, Dee Moore, Heather Quammen, Pat Schaffner, *Musicians:* Steve Anderson, Amy Kuebelbeck, Tara Lyons, JoAnn Rivard, Christina Ufer-Kane *Parents:* Karen Erickson, Janet Farmer, Desiree Fleming, Sandy Tranby, Les and Jennifer Ten Eyck

#### Camp Connect

Lisa Bornemann, Jenny Cook, Tom Dodge, Linda Lehmann, Todd Mack, Vicki Neis, Chris Radecki, Sarah Ridgway, Christina Ufer-Kane, Joan Ward

#### Compassion Connection

Don Brunnuell, Bert and Laurel Fraher, Brian and Kate Hanson, Susan Lacek (Faith's Lodge) , Linda Lehmann, Vicki Neis, Barbara Rudnick (Jewish Healing Services)

### Looking For Ways To Support Healing Quilt? Here's How:

#### **Volunteer**

- Become a Parent to Parent volunteer
- Serve on the Healing Quilt Advisory Committee
- Help with A Beautiful Night fundraiser
- Help plan and carry out Healing Quilt programs (support groups, retreats, memorial services, staff education)
- Write articles for the Healing Quilt newsletter

#### **Donate**

- Donate to the program to help us offer bereavement support to families at no cost to them
- Contribute to a Memorial Sponsorship for the fundraiser
- Donate items for the silent auction
- Become a corporate sponsor to the fundraiser or seek a sponsorship from your place of employment

- Attend the fundraiser, bring your friends
- Donate gift cards to the following:
  - Michael's (art and craft supplies used in support groups and retreats)
  - Cub, Rainbow (refreshments for support group meetings, camp, retreats, memorial services)
  - Barnes and Noble (books for adults on grief, or bereaved siblings)
  - JoAnn Fabrics (for material used in grief packets, retreats, memorial services)
  - Gift cards (for miscellaneous expenses)

**For more information, contact Linda Lehmann, (612) 813 6622.**



# Calendar of events

For more information or to register, call Linda Lehmann, (612) 813-6622.

### Fall 2008 Evening Grief Groups

**Place:** St. John the Evangelist Episcopal Church  
60 Kent Street  
St. Paul, MN 55102  
**Time:** Tuesdays 6:45-8:00 p.m.  
**Dates:** September 23  
October 7, 21  
November 11, 25  
December 2

#### **Adult groups offered:**

- Spouse/Significant Other Group
- Infant Loss Group
- General Bereaved Parent Group
- Bereaved Parents Whose Child Died After Lengthy Illness

#### **Child/teen groups offered:**

- Pre-School
- Grades K-2
- Grades 3-6
- Teens

### Fall 2008 Daytime Grief Support Group

**Place:** Children's Hospitals and Clinics of Minnesota, St. Paul campus, Garden View Medical Building  
**Time:** Wednesday, 10 to 11:30 a.m.  
**Dates:** September 10, 24  
October 8, 22  
November 5, 19  
December 3, 17

Childcare provided and preschool grief group offered at the same time.

### Pregnancy and Infant Loss Support Groups

For those who have experienced a perinatal loss. Meets the 2nd and 4th Monday of each month on the St. Paul campus. To register call Annette Klein, (651) 241-6206 or Brian Brooks (612) 813 7346.

### Sorrow and Soaring: A Journey Of Love (Perinatal Memorial Service)

**Place:** 245 Smith Avenue  
St. Paul, MN  
**Date:** Saturday, October 4, 2008  
**Time:** 1:30 p.m.

### Mom's Retreat

**Place:** Faith's Lodge, Webster, WI  
**Dates:** Saturday, October 13 to Sunday, October 14, 2008

Join us for our first overnight Mother's Retreat. Meet other bereaved Moms at beautiful Faith's Lodge in northern Wisconsin, a retreat center, designed specifically for bereaved families, that invites you to reconnect with your child who died and to soothe your grieving heart. This retreat will be designed to help you connect with other moms while, at the same time, give you an opportunity to be alone if you like, as you honor and reflect on the life and death of your child.

### A Beautiful Night

**Place:** Water and Oil Art Gallery, (Located in St. Paul's historic Swede Hollow, 501 Kenny Rd, St. Paul, MN [www.waterandoil.com](http://www.waterandoil.com))  
**Time:** 7 to 11 p.m.  
**Dates:** Saturday, November 15, 2008  
**Ticket:** \$40

Join us for our annual fundraiser, "A Beautiful Night," at St. Paul's newest art gallery. The evening will include wine and chocolate tasting, appetizers, silent and live auction and much more. We depend on this fundraiser to support the many programs we offer at no cost to families. If you would like to attend or are interested in helping out with the fundraiser, call Linda Lehmann at (612) 813-6622. Thank you for your support.





## Remembering Andrew: My grief through the years

by Jennifer TenEyck

My son Andrew died seven years ago at the young age of five. During these past years without Andrew, I have visited both ends of the spectrum; I have endured tremendous pain in losing someone I love and I have gained a deeper appreciation for the people in my life. While losing Andrew has left me with immense holes, I have also gained vast insight. Losing Andrew has changed my perspective on both love and life.

Losing Andrew has been the most difficult loss I have ever experienced. No one expects to outlive a child. I still experience deep sadness when I think of Andrew and of all that I have lost. I lost a beautiful, smart, affectionate little boy—my firstborn child. I am still amazed at how painful his loss is when I think of what I had and how he should still be here. For me, the “should have beens” and “what would he be like” are the most difficult to endure. He should have been twelve and he would be the oldest of five kids. I wonder what he would look like, what his interests would be and what our family dynamics would be like with two boys plus our three girls. After having two boys first, I miss being able to say “my boys!” Little things like the loss of an expression cut very deeply for me.

I now have a greater appreciation for the people who matter in my life. Before I lost Andrew, I knew of death, but I had never experienced it. With Andrew, death became reality as I experienced just how tenuous life is. I now hug my kids longer and more tightly. I am a better listener and I am more acutely aware of people’s needs. I do believe I appreciate life more than ever before because I lost Andrew.

The most insightful aspects I have learned about grief are how painful, enduring, and private it can be. Because

*Healing Quilt 2008 Revisited, continued from page 1*

**Healing Quilt web site:** Information about programs and grief online.

**A Beautiful Night fundraiser:** A once-a-year fundraiser to support the programs of Healing Quilt.

**Photography project:** Staff have been trained to take more professional photos of children who are dying or who have died as lasting mementos.

**Compassion Connection:** Staff education around issues related to grief and loss.

**Wrapped in Care:** A new program in which shawls are given to moms in the NICU whose baby is dying.

**Grandparent Gathering:** Informal quarterly meetings for grandparents.

Andrew died, I carry around this enormous sadness in me. It is ever present and bubbles up to the surface in deep waves from time to time. A memory will spark my grief or an expectation of what my life should be will ignite my pain. Yet my grief is intensely private. Because I carry these feelings deep in my heart, the average person doesn’t even know my pain. I believe one of the most difficult aspects of grief is the solitude of it. As years pass, fewer people mention Andrew’s name or call on his anniversary. I do realize this is a natural progression over time, but it doesn’t necessarily make it any easier for me.

And yet I feel intense hope. Yes, grief can be very private, and the “could have been/should have beens” do overwhelm me from time to time, but I feel incredible optimism too. Andrew’s life was short and definitely over too quickly, but he taught me to love with all of my heart and to enjoy every day no matter what it held. While others continue on with their lives, as Andrew’s mom I can see that his memory lives. By living my life positively, by telling his story, I am honoring Andrew.

Losing Andrew has left me forever changed. I know how painful loss can be and how wonderful life is all at the same time. While I cannot change what happened with Andrew, I choose to do my best to summon up my courage to carry on positively each day even in the face of many fears. By living my life graciously one day at a time, I find I am honoring my grief and Andrew in the best way I know how.

*Jennifer is a Parent-to-Parent volunteer and co-facilitates grief groups offered by Healing Quilt with her husband Les.*

### Healing Quilt in the future

The earmark of a vibrant bereavement support program is to be flexible and to respond to the changing needs of the community and the families we serve. It also means offering, unique, creative programming that appeals to a broad range of children, teens, adults, and families without duplicating existing services. As our community becomes more diverse, it challenges us to be culturally sensitive to the needs of families who may not speak English proficiently. As families become more complex and mobile these trends will also continue to challenge us as we strive to carry out our mission and goals in the months and years to come. We are committed to this mission and continue to be deeply touched by the profound sense of loss families experience when their child dies as well as the enormous courage they display as they live out their lives with purpose and intention.

## Grief guides:

### Fall Schedule for Faith’s Lodge

September 9-14	Bereaved parents-Infant Loss- planned activities
September 16-21	Bereaved parents-Child Loss (Children who died ages 1-19) - no planned activities
September 22-28	Bereaved families- planned activities
October 11-12	Mom’s Retreat sponsored by Healing Quilt
October 14-19	Bereaved Families-planned activities
October 28-November 2	Bereaved parents-Child Loss (Children who died ages 1-19) – planned activities

For more information, contact Faith’s Lodge at (715) 866-8200.

### Buy 2009 “My Favorite Dream” Calendars and Support Healing Quilt and Hospice Pain and Palliative Care At The Same Time!



Healing Quilt and Hospice Pain and Palliative Care programs are currently taking orders for 2009 calendars. The calendars feature drawings created by bereaved siblings reflecting on “My Favorite Dream”. The siblings range in age from age 4 to age 16 and are sure to delight and inspire anyone who receives this one of a kind calendar. They would make great holiday gifts. Cost of the calendars is \$15.00. To order one (or more) please fill out the form below and mail with your check to:

**Children’s Hospitals and Clinics of Minnesota**  
2525 Chicago Avenue South  
Mail stop # B-500  
Minneapolis, MN 55404  
Attn: Linda Lehmann

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

Please state # of calendars you would like to order at \$15.00 a calendar

# of calendars: \_\_\_\_\_

Enclosed is a check in the amount of: \_\_\_\_\_

Please make checks payable to: **Children’s Hospitals and Clinics of Minnesota**  
**A Beautiful Night**



# How to be your grieving child's best advocate in school

by Linda Lehmann, bereavement coordinator

contributors: Diane Dingley, child life specialist and Theresa Huntley, social worker

When a family member dies, it can turn a child's world upside down in many ways. It affects children and teens physically, socially, emotionally, and mentally. While children aren't always able to tell us they are grieving, they will show their grief with their bodies and with their behavior. That's why you, as your child's parent, may have to help others understand your child's grief.

As the school year begins, you can be an advocate for your child at school. Try not to assume that all school personnel understand childhood bereavement. You can help them understand how children grieve, and most importantly, how your child grieves.

The chart below shows some of the common, normal grief reactions of children and teens. Remember, you are the expert about your child.

Physical reactions	Mental reactions	Emotional reactions	Social reactions
<ul style="list-style-type: none"> <li>• Sleep disturbance</li> <li>• Appetite disturbance</li> <li>• Stomachaches</li> <li>• Headaches</li> <li>• Frequent colds or illnesses</li> <li>• Fatigue</li> </ul>	<ul style="list-style-type: none"> <li>• Short term memory loss</li> <li>• Short attention span</li> <li>• Highly distractible</li> <li>• Preoccupied with the loss</li> <li>• Difficulty concentrating</li> </ul>	<ul style="list-style-type: none"> <li>• Wide mood swings</li> <li>• Short fuselrritability</li> <li>• Detachment</li> <li>• Marked changes in behavior (either better worse)</li> </ul>	<ul style="list-style-type: none"> <li>• Aggression toward others</li> <li>• Withdrawal from family or friends</li> <li>• Disinterest in normal activities</li> </ul>

Here are some ways you can be an advocate for your child at school.

**At the beginning of each school year, it is important to talk to your child's teacher.** Your child may have a new teacher or a new set of teachers who may not know your family's story. Before the school year begins, talk with your child about how much information they'd like to share about the death of your loved.

Parents of younger children may want to play a more active role when talking with their child's teacher. Parents of adolescents may want to talk with their child first about what will be shared with teachers. What role does your child want you to play in speaking with the teacher? What parts of their story do they want or not want to share? The amount and kind of information that is shared may depend on how recent the death was. Or it might be important to share this information no matter how long ago the death occurred.

Your child's teacher will need to know how to recognize your child's grief in the classroom. Talk with the teacher about how best to respond to your child's grief. Tell the teacher it is

important to be able to talk openly about any problems that may come up during the school year. You may also want to assure the teacher that you, too, will keep them informed about any changes or added stress in the family. Meeting with your child's teacher will help to ease the adjustment for your child as the new school year begins. Be sure you tell your child once you have had this talk with the teacher.

**Grief can affect your child's ability to learn.** Schoolwork can be particularly difficult when a child is grieving. Short-term memory is greatly affected when a child grieves. They may be preoccupied, which may be interpreted as daydreaming. This can affect a child's ability to learn. Work with your child's teacher to make sure there is some flexibility and reasonable expectations for your child. If problems come up, explain that you want to hear about it right away so that you can work together to keep your child from falling behind in schoolwork.

It is common for children who are grieving to be much more distracted and have shorter attention spans. They may also display hyperactive behavior. These symptoms are also very common in children who have attention deficit disorder (ADD), or attention deficit hyperactivity disorder (ADHD). If your child did not display these behaviors before the death, but now displays this behavior often, it may not mean that she has ADD, but rather is grieving. You can help school personnel understand the effect that grief can have on a child's ability to concentrate and sit still.

Ask your child's teacher how comfortable he or she is with your child openly talking in school about the loved one who died or not talking about the loved one at all.

Some families have said that some teachers have discouraged their child from openly talking about his or her loved one who died in school, and even going so far as to question whether this is "abnormal" behavior. Sharing stories, remembrances, speaking their loved one's name in school may seem very natural and desirable to some children.

Reinforce to your child's teacher that expressing grief is healthy and normal. On the other hand, some children find it difficult to talk about their loved one in school at all. In those cases, children should not be forced to talk about anything they don't want to discuss. The fact that a child chooses to keep this information very private does not mean that he is not grieving.

*How to be your grieving child's best advocate in school, continued on page 5*

*How to be your grieving child's best advocate in school, continued from page 4*

## Help your child's teacher understand that grief can go underground and surface again at a later time.

This means that even though a child may not appear to be grieving, she still is. The grief often resurfaces at critical developmental milestones such as a major grade change, a new school, during the holidays or birthday of the loved one who died. The fact that a child appears to be doing okay doesn't always mean much. It simply means that the grief has gone underground and will surface again off and on as the child grows up. Any change in a bereaved child's life can trigger her grief and make it difficult to cope. The beginning of the school year is a big change in a child's life.

## Some classroom assignments may trigger a child's grief.

An example might be to ask a child to draw a family picture or make a gift for a certain family member. These assignments may seem harmless on the surface, but can be very upsetting to a child who has had a family member die. They are faced with a huge dilemma. Do I draw my loved one into my picture or leave them out? How do they answer the question "How many people do you have in your family?" How can I make a Mother's Day gift when my mother just died?

## The feelings of grief can be overwhelming.

Sometimes grieving children can feel overwhelmed with their grief and may not want their classmates to see its intensity. When this happens, some children (not all children) may need a safe place to go within the school to regain their composure. Grief can ambush all of us when we grieve, even children. Having a safe place to go helps children to have some control over something that feels uncontrollable.

## Some children find it difficult to be away from a parent during the school day and may refuse to go to school.

School can be very comforting to children because it may be one of the few things in a bereaved child's life that can be counted on after a family member has died. While family life can be greatly altered by the death of a family member, school remains the same. Having the same classroom, the same classmates, the same teacher, and the same schedule each day can be very reassuring to a grieving child. When a child is reluctant to go to school after the death of a family member, it may be because he fears for the parent or other family members at home. To help ease separation fears give your child an object that he associates with you to keep in his backpack.

Healing Quilt staff who specialize in childhood bereavement are available to assist your efforts in supporting your child. If you have any questions or concerns, please call Linda Lehmann, bereavement coordinator, at (612) 813- 6622; Diane Dingley, child life specialist, at (612) 813-7378; or Theresa Huntley, social worker, at (651) 220-6904.

