



REFLECTIONS

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How Grief Has Changed Us ...From a Parent's Point of View

By: Debbie Gemmill c1996

We moved into a new neighborhood recently, into a cute little house on a corner with fruit trees and roses. It's the house we've been waiting for, and moving into it was exciting and wonderful. For the first time in several years, we are surrounded by an entire block of people who don't know our history.

No one was more surprised than I when I didn't rush out, knock on all the doors, and introduce myself by saying "...and my second child died of Sudden Infant Death Syndrome."

It wasn't that long ago that that's exactly what I would have done. Ty's death, so sudden and unexpected had shaken me to my very core, and it was nearly impossible to keep from telling everyone, strangers included, about this terrible tragedy that had befallen our family. At times, it felt as if I was telling a very sad story about some other family, and it seems that it took several retellings before I really believed both the tale and the list of characters—*our* family...*our* son.

The sinking in of reality, slow and gradual in comparison to the jolt of his death, came at a time we were least able to deal with it. We were being bombarded by so many emotional and physical challenges. I didn't know then that some of the changes I was experiencing would turn out to be temporary; sleeplessness, forgetfulness, restlessness. More importantly, I had no way to know that some of the other changes would leave a permanent mark, and in many ways leave me as a familiar form, but quite a different person. A better person? I doubt it.

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A Note From The President

I have watched my mother slow down over the past few years. Her step is guarded, her vision has clouded with Macular Degeneration, and her mind seems to be slipping. She lives alone in San Clemente—40 minutes away from my home. My mother's loneliness is palpable. When I arrive for my bi-monthly visit, she hangs onto my arm a little longer than she needs to and begs me to tell her the trials of my life. What is the latest on Krist and Kevin? How are they doing in school? Which college will Krist attend? Is Laura engaged yet? I answer her questions and move on to pay her bills, fill her medication box, take her to lunch, and rush back to my hectic, fast-paced life.

My time is not my own. It is filled with being a single parent to two teenagers, shopping for colleges, two jobs, advanced college work, and too many animals. Each second is filled with something – analyzing compensation structures for my day job, writing a lesson plan for my night job, researching for a college project, organizing one of my sons' schoolwork, answering SIDS emails, making lunches...the list never ends. And at the end of the day, I don't feel like I have done anything good enough. I'm sure many of you can relate to this statement. We take on projects with the best of intentions and somehow aren't able to follow through like we used to – like we might have done when we were 30 years old.

Well, menopause and the anticipation of turning 50 this summer have started to slow *my* step recently. I have had to reassess the activities that fill my days and determined that something has to give. After much thought and prayer, I tendered my resignation from the position of President of the Guild for Infant Survival, Orange County effective September 2008. It is time for someone younger to take over the reins of the organization and bring us into the next year with renewed energy and enthusiasm.

I hope that you will consider stepping forward to help the organization restructure its board and responsibilities. The new board will need greater participation from parents in order to achieve its goals and mission. You, the younger generation, can assist newly grieving parents like no one else can. It is *you* that these parents want to speak to and *you* that have the means and contacts to help raise research funds for the eventual eradication of SIDS. Please consider filling a position in September. It is a wonderful way to memorialize your son or daughter.

REFLECTIONS

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Editor: Cory Morinishi

Reflections is a quarterly publication of the Guild for Infant Survival, Orange County—a non-profit organization. *Reflections* is committed to the collection and dissemination of accurate, up-to-date, scientific and lay information and the correction of misinformation related to SIDS. The Guild is dedicated to the support of families and friends suffering the death of an infant to SIDS.

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Newsletter Deadlines

If you would like to contribute an article or poem to an upcoming issue of *Reflections*, please contact: Cory Morinishi at (714) 952-1466 or e-mail him at sharmori@ca.rr.com. The next Newsletter deadline is 5/15/08. We encourage your participation!

How Grief Has Changed Us ...From a Parent's Point of View

(Continued from Page 1)

Losing Tyler has left me suspicious, fearful, angry at my inability to control my life, and more than a little jealous at those whose lives follow the “white picket fence” script I’d written for my own family. It’s made me an overprotective parent to both my surviving and subsequent children. I still can’t, after seven years, let either of them out of my sight without taking one long, last look, so that I’ll remember just how they look in case they don’t come home. I fight these feelings and rarely voice them, but they are always there with a grip that doesn’t seem to loosen, even after all this time.

John and I spent the first eight years of our marriage thinking all children grow up. We’ve spent the last seven years living with the reality that they do not. Ty’s death and the paralyzing pain it caused seemed only to emphasize every single individual difference in our personalities. The experts call it a “gender difference in grieving” - for us it was a frightening aftershock that threatened what seemed like our last hold on security. Thank goodness SIDS didn’t take away our marriage as well as our son, although I know it is one more thing I will never again take for granted. I can’t seem to fall asleep until I’ve listened carefully to make sure that John, too, is breathing.

Grief seems to tire itself out after those first few awful weeks and months. Instead of attacking with a vengeance, after a while it lurks in the background and just sort of sucks the life out of you. I stopped crying every day a long time ago, and even the holidays are fun again, but my son’s death sits in my heart and takes up the space that should be there for his life.

It is not all grim. Some things have gotten better, as I can look at sleeping babies now without feeling for a pulse, and I can congratulate expectant parents without putting aside a SIDS packet, just in case. But I still can’t hear a siren without stopping in my tracks and reliving the sensation of being in the front seat of a racing ambulance with the horrible knowledge that the trip was for nothing. I can’t visit a hospital nursery without scanning those wrinkled, pink, gorgeous faces and wondering which ones won’t have a first birthday.

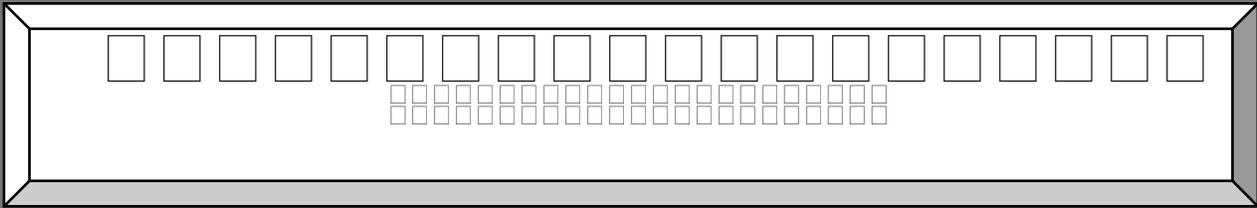
Some people really do believe that something like this can make you a better person. I can’t quite see it, but I do know that we all have choices. SIDS has dealt our family a cruel hand, but I guess it is up to us to decide how to play the cards.

When we started meeting our new neighbors, the inevitable question was asked: “How many children do you have?” I used to really struggle with that one, but this time—without hesitation—I answered: “*Two.*”

For, in spite of all the euphemisms I’ve used in the past to explain Ty’s absence, two really *are* all the children I have. The third was stolen away. And I will never forgive nor forget the thief.

It’s inevitable, I suppose, that eventually as our new neighbors become our friends they will ask about the unfamiliar fuzzy-headed baby in the picture on the piano. My guess is that they will feel sad for us, and be a little surprised that somehow they didn’t already know. How could they? We appear, I think, pretty “okay” on the outside. We picked up the pieces a long time ago; we don’t spend much time sifting through the shambles. We’re active, productive people. Our neighbors have no way of knowing that the people who moved into the house on the corner always thought they’d have a white picket fence. Instead they have fruit trees and roses.

And two children.



sibling who was not born at the time of his brother's

response to this problem in the old adage: "You can't miss what you've never had." Experience and

am." Does a subsequent child feel like the "replacement child," as if they somehow have to fill

there is a vague sense of emptiness that we can't

Wrapping a cot mattress in plastic does not explain the continuing fall in SIDS mortality

(Continued From Page 5)

The aim of this study was to determine the prevalence of cot mattresses wrapped in plastic, describe the characteristics of families that wrap the cot mattress and finally to compare this with changes in SIDS mortality. The study received ethical approval from the Auckland Regional Ethics Committee. There were 508 infants born from 24 February to 20 March 2005 at National Women's Hospital in Auckland, New Zealand. The infants were allocated a random number and the birth list was sorted by the random number, with the first 200 being selected. A similar process was used to select a second group of infants. There were 612 infants born between 15 January and 14 February 2005. In April-May 2005, a questionnaire was mailed to the 400 mothers of the selected infants who now were aged 6-8 weeks and 3-4 months, respectively. The outcome of interest was obtained from the question: "Do you use plastic wrapping over baby's mattress (so that the mattress is completely covered in plastic?)".

The response rate was 70%. Overall, 21.7% of cot mattresses were covered in plastic. Parents who enclosed the cot mattress in plastic were more likely to be European ($p=0.016$), place the baby to sleep supine ($p=0.030$), not place the baby to sleep in the parents bedroom ($p=0.014$), not bed share with the baby ($p=0.031$) and be a non-smoker ($p=0.069$).

SIDS mortality has declined 63% from 1994 to 2004 (Fig. 1) [6]. The prevalence of plastic wrapped cot mattresses has remained constant since 1997 (Table 1).

The decline in SIDS cannot be explained by changes in the proportion of plastic-wrapped cot mattresses. Although the wrapping of cot mattresses has been recommended by proponents of the toxic gas theory in New Zealand since December 1994, approximately 22% of infants sleep on a mattress that is wrapped, and this proportion has remained constant since 1997. Case-control studies have not shown that wrapped mattresses protect against SIDS [2,10]. Even if the mattress wrapping was completely effective in preventing SIDS, it could only produce a 22% reduction in SIDS compared with the 63% decrease in SIDS actually observed, unless those infants who slept on a plastic wrapped mattress were at high risk of SIDS. In fact, the opposite was seen. The parents were more likely to be European, sleep their baby supine, not bed share and be a non-smoker. All these factors are associated with a reduced risk of SIDS.

The strengths and limitations of the study must be considered. In the Auckland District Health Board, all infants are born at National Women's Hospital with the exception of a small number (<4%) that are born at home. Thus, the eligible sample is close to being representative of all births in the study region. Although the participation rate was 70%, which is considered to be good for a postal survey, participants may be more likely to comply with health messages. Non-participants were more likely to be non-European, which had a lower prevalence of mattress wrapping in this study. Thus, the prevalence in the total infant population is probably less than the 21.7% estimated in this survey. No information other than ethnicity was available from non-participants.

Many other countries have shown a similar trend in SIDS mortality, namely, a rapid decrease in SIDS mortality following the introduction of the "Back to Sleep" campaign, followed by a slower decline [1], and these countries have not encouraged mattress wrapping.

In conclusion, wrapping cot mattresses in polythene does not account for the continuing decline in SIDS.

Heaven Date

**By: Carlene Vester Enroth
Spokane, Washington
Reprinted From Bereavement Magazine**

A special date is looming large on the calendar, isn't it? It's one you've dreaded for practically 360 days or so...the date of your special person's death. I like to call it our "Heaven Date." If you're like I was, you aren't quite certain what happens to people on those days. Do they just ignore the day, keeping busy and pretending it isn't here? Do they spend the day sitting at the cemetery? Or, my worst fear, do grieving people somehow just literally lose their minds on that day? I had no idea and it scared me. You too?

First of all, I think you need to stop, take a deep breath and literally pat yourself on the back. Go ahead; do it! You deserve that pat and lots of applause because you have survived a horrendous year. Take the time to sit back and think of all that you've survived – all those "first" birthdays, Christmas, start of school, Mother's Day, Father's Day, and the list goes on and on. Those are all huge hurdles to overcome in grief, and you have survived each of them. Congratulations!

Still the question begs to be asked: Just what do people do on that Heaven Date? We know it's not possible to forget, and if forgetting meant we weren't acknowledging our special person, then we want no part of that either. Well, here are some ideas from other survivors along the way:

Invite a friend to go to the cemetery with you and take along some helium balloons. Let them go at the same time, sending them on to Heaven.

Take special day trips and see some of the sights (museums, the ocean, a favorite camping spot) that they would have enjoyed. If it means you have to take the day off from work, that's okay. Our Heaven Dates are special memories in our families, and they always will be.

One father I know brought his wife a long-stemmed, silk rose on their daughter's Heaven Date. Her mother said, "I guess I had such a good reaction that he did it again the next year –and the next. I put them in a bud vase in the entryway. It's been several years now, and he's still remembering Judy in this way. The little bud vase has given way to a much larger vase, and this lovely bouquet of silk roses is a great way to bring up Judy's name when company steps into our home." Neat idea, isn't it?

A Canadian family donated books to the county library in their daughter's name each time her Heaven Date came up. They could keep her name in print by placing special labels inside each of those books.

You probably have even more creative ideas than the few I have listed here. Every time I get to talk to new survivors, they stun me with their creativity in things like this. But one thing is certain, please don't plan to just sit home on that first Heaven Date. You may have to work, but at least plan a special lunch time away from the office. If you aren't working, plan volunteer projects, a visit to the outlet mall, some fishing on a favorite lake or exploring a new park. Staying home just gives our brains too much time to think and the whole day goes south.

And just per chance, would you be a friend to a new survivor? Did you know that you have the ability to make this Heaven Date about as good as it can be? Take a minute to call or write that friend and say that special person's name out loud. Use their name in conversation. Whew! Nothing is as wonderful as getting to hear that name again. It seems so long since anyone has done that. We will be forever grateful to you for your touching thought in remembering.

MEMORIAL DONATIONS

Donations have been made in loving memory by those who loved them:

In Memory Of Mathew Gaalswijk

Marcia Gaalswijk-Knetzke
Saxon, Gilmore, Carraway,
Gibbons, Lash & Wilcox P.A.
Pete & Liz Gaalswijk

In Memory Of Maria Gaalswijk

Karen A. McHugh
Marion and Willard Ulmer
Robert G. Ryan

In Memory Of Ryan Joseph Jahn

Constance M. Hempel
Emmett & Laura Black
Lisa Renzo

In Memory Of Jamie Lynn Dow

R.H. & D.M. Mark

In Memory Of Cory Eckert

Diane Gelormino

In Memory Of Jason Alexander Robar

Robert and Susanna Robar

In Memory Of Jason Doo

Canyon Hills Women's Club

In Memory Of

Jon Craig Malcommson

Gary & Jane Malcolmson

Helen M. Craig

In Memory Of Sarah Ashley Robbins

Margaret & Iain McCormick

In Memory Of

Scott Francis Hogan "Scotty"

Beck & John Hogan

In Memory Of

Ian Russell Anthony Watson

Russell & Toni Hudson

In Memory Of Kaylee Rene Billings

Dale & Judy Dunbar

In Memory Of Adam Brittain

Andrew & Dorothy Clay

In Memory Of

Christopher Bryon Phillips

Marie T. Bowen

In Memory Of Hayden Strickland

Love, Grandpa and Grandma

Newsletter Donations

The cost to print and mail the *Reflections* newsletter is steadily rising. Therefore, it is important that we have your latest contact information. If the address shown on your newsletter is not correct, please e-mail Barbara Estep at gisoc@compuall.net or call her at (714) 973-8417 with your current information.

Newsletter donations of \$20 covers the cost of printing and mailing quarterly newsletters. Mail your donations in today.

Written By: Sally Silagy (Compassionate Friends)

I am past intense grief, but not loss
Past questioning, but not wondering
Past relentless sobbing, but not crying
Past guilt, but not regrets
I am simply years into my grief
And life as it has been defined by the
Absence of my child

The Myth Of Closure

By: Ashley DavidPrend (Hospice of North Idaho)

"When will I begin to feel better?" "When will I return to normal?" "When will I achieve some closure?" grievers often ask.

Closure, our culture tells us, will bring about a tidy ending, a sense of completion. Some grievers hope that the desired magical closure will occur after the funeral or memorial service. Others are confident it will come once they have cleared out their loved one's room. Or maybe after a special personal ritual. Or perhaps after the first anniversary comes and goes. "Surely then, we will have closure", we think. We pray.

The reason we long for closure, of course, is because we would like to neatly seal away all of this pain. We would like to close all the sad, confused, desperate, angry feelings out of our life. We would like to put all of this behind us.

Closure. What an odd concept really, as if we could truly close the door on pain--turn the lock and throw away the key. The truth is far more complex, of course.

Closure is for business deals. Closure is for real estate transactions. Closure is not for feelings or for people we love.

Closure simply does not exist emotionally, not in a pure sense. We cannot close the door on the past, as if it didn't exist, because, after losing someone dear to us, we never forget that person or the love we shared. And, in some ways, we never entirely get over the loss. We learn to live with the loss, to integrate it into our new identity.

Imagine if we really could end this chapter in our life, completely. It would mean losing our memories, our connections to those we love. If we really found closure, it would ironically hurt even more because the attachment would be severed. And this attachment is vital to us--the memories are treasures to be held close, not closed out.

Perhaps it is better to think in terms of healing. Yes, we can find ways to move on and channel our pain into productive activities. Yes, we can even learn to smile again and laugh again and love again.

But let's not ever think that we'll close the door completely on what this loss means. For, if we did that, we would unwittingly close the door on all the love that we shared. And that would truly be a loss too terrible to bear.

Related SIDS News

SIDS Foundation of Southern California will be holding their 28th Annual Walk and Picnic Sunday, April 27, 2008. Registration and breakfast 8:00 - 9:15 AM, Walk 9:30 AM. There will be lunch and a raffle. The event is being held at Whittier Narrows Regional Park, 715 S. Santa Anita Avenue, South El Monte, CA 91733 (west of the 605 Freeway, south of the 60 freeway). Bring a children's book for a special raffle. For more information call (310) 558-4511.



2008 MEETING CALENDAR

Parent Support Meetings– All meetings are from 7:00—8:30 PM.

* Please RSVP to the parent host prior to the meeting

May 15, 2008
(Thursday)

Home of Lisa Biakanja
20732 Alicante Lane
Huntington Beach, CA 92646
RSVP to (714) 960-9897

July 8, 2008
(Tuesday)

Home of Rachel Strickland
2828 East Puritan Place
Anaheim, CA 92806
RSVP to (714) 630-0400

Business Meetings– Business meetings are held at the home of Lisa Biakanja located at 20732 Alicante Lane, Huntington Beach, (714) 960-9897. Meetings begin at 7:00 PM. If you would like to have an item added to the agenda, please contact Lisa at (714) 960-9897 or lbiakanja@yahoo.com.

May 22, 2008

August 20, 2008



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