

Day
of the
Dead

The Personality
of Support

and more...

Different Kind of Parenting:

A 'zine for Parents
whose children have died

Levi's
Story

Memorials

Twenty-Six Years:
Perspectives
on Grief

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Notes from the Editor

It is winter again here in the Northern Hemisphere, and I am somehow comforted by the changing leaves and the pale days. It may have something to do with all the awareness and memorial activities that happen at this time of year, too. We seem to start off winter by having our son's life and death affirmed as a reality for us. Many things happen to give tangible light to the continued process of coming to terms with life after the death of a child.

October is Pregnancy & Infant Loss Awareness Month, and October 15th is Awareness Day. There are walks, candle lightings, teddy bear drives and other events around the world where people are honoring the lives and deaths of their babies. If you want to know more about events happening where you are or how to organize something yourself for next year, please see:

<http://www.pregnancyandinfantloss.com>

It is also the season of Day of the Dead. This is a celebration of Mexican traditions that is just an amazing time of honoring our loved ones and acknowledging how much they still influence our lives. There is a little write up on page 5 about it, with links to other websites offering information.

And so this issue, we offer articles by bereaved parents who are honoring and remembering their children. We talk a little about the personality of support. And we just hope you find a little something here to get you through the days as they turn a bit colder. Make some tea, wrap up in a blanket, and hopefully find a bit of comfort here.

Miracles to you all!

Kara L.C. Jones
Editor@KotaPress.com

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The Personality of Support

By Kara L.C. Jones

This idea of “the personality of support” came up when Joanne Cacciatore and I spoke about the MISS Passages 2003 Conference coming up next Spring. In discussing ideas for a panel discussion at the conference, we hit upon the idea that every support group carries with it, the distinct personality of the person running the group. We explored a little more about how the group and type of support offered might become expression for the bereaved parent who facilitates the group. I began thinking of this outside the confines of just in-person support groups and expanded the definition of support a little.

It's turning out to be a most interesting investigation, and I'm happy to tell you that we will be doing a panel discussion about the Personality of Support at the 2003 MISS Conference! The panel is geared toward facilitators, but it will be open to anyone attending the conference. And our hosts for this panel will be:

Katie Hodge, Director of Operations, MISS Foundation
Nancy Grayson, Founder & Coordinator for MISS Idaho chapters & affiliations
Hawk Jones, Founder of KotaPress, Coordinator for WA MISS chapter
Kara L.C. Jones, Founder of KotaPress, WA MISS Coordinator, NSS Director

We will talk about all the variations you might see in MISS chapters across the U.S. and in Mexico where we now have active chapters. I hope we can cover the personality of in-person support groups as well as online outreach such a forum boards, discussion groups, email pen pals, ezine and more. We'll look at how a group of any kind grows and then how and when the group may or may not split into sub-groups that discuss more and more specific situations where people need support. We'll address some of the basics like holding in-person groups in hospital settings vs. non-hospital settings; creating a safe space online for discussion and support; what to do when the group no longer matches your personality or when you need some additional support as the coordinator.

My hope for this panel is to show that the personality of support is as varied and different as each of us is varied and different in our own perspectives and experiences of grief. And to show that this is OKAY! I run into too many parents who had support for awhile, but then something changed. They turned a corner in their grief, or the group started to become a subsequent pregnancy group which isolated the people who are not getting pregnant again, or the coordinator for the group decides to stop doing that work. And too often, those parents feel like they did something wrong or that they somehow failed in their search for support. I'm hoping to show with this panel, that it is all individual and constantly changing, and so it is okay to seek out the support that best suits your personality. And if things change for some reason, then it is okay to seek support in some other way, place, or format. This isn't a test that you pass or fail. It's life after the death of a child. It is OKAY to take care of you in whatever ways you need!

So, I hope you will join us for more discussion at the MISS Passages 2003 Conference. For more information about the Conference and registration, please see:

<http://www.missfoundation.org/events.html>

Levi's Story

By Gail Lindekugel

The night my second child was born, all seemed uncertain. Induced five weeks early because of a leakage of amniotic fluid, the Doctor had remarked, "Sometimes these early ones just don't make it."

I remember the stillness of the night, my breathing, intermixed with sighs and groans as I labored to bring our son into the world, frightened that he was safer in my belly than out of it.

But make it he did, weighing just over five pound Levi arrived, grunting instead of crying, he was whisked off to the NICU where he would spend the next 4 weeks learning to live in the world. Step by step, from the respirator to the isolate to, finally, room air he made his way toward home. In the mean time I sat beside him, feeling more attuned to the bells and whistles of all his equipment than to him. When I was with him, I missed my daughter, then two years old. I knew what to do for her, could touch her, carry her, hold her to give comfort.

When I was home I missed Levi, thought of him a scant 7 blocks away from our home, at the hospital. I wondered how I would ever learn to take care of him.

People did not know how to respond, no flowers or baby gifts this time, just looks of concern and whispers of, "We are praying for you."

Finally one month after his birth, on his due date Levi made the trip home. On a whiff of oxygen and connected to the apnea monitor he was finally with us.

We adjusted, the oxygen was only for a month and the apnea monitor, which he never alarmed except when he kicked off his wires, was a thing of the past by 8 months.

I was so fearful of having another child. It was nearly 4 years until our third child was born. Kealan's birth went off without a hitch and just as I began to relax and trust the world again Levi was diagnosed with a cancer called neuroblastoma. He fought so bravely for nearly 3 years and died, on a still winter's night, in a rooms hushed except for the sounds of his struggled breaths and groans.

Again came uncertainty and fear, but also the hard knowledge that Levi was safer to return from where he came rather than to remain in a little body that had so let him down.

As Levi struggled in labor, in a sense to give birth to his spirit, his hand gently stroked and cradled by his 84 year old great-grand father, his baby brother asleep at the foot of his bed, his father and sister at the head of his bed and I , his mother lying beside him feeling his tired heart slow and finally stop. I was struck by the terrible beauty of it, the sacred duty entrusted to us to welcome this child into the world, to love him for nine short years and then to see him off as he returned to the light that created him.

For more about Levi and Levi's family, please see: www.lanefrost.com/laneslegacy.htm

Twenty-six Years: Perspectives on Grief

By Susan Wilson

Twenty-six years seems like a long time to miss someone. Our firstborn, Matthew Greer Wilson, was born November 15, 1976 and left us on December 12 the same year. He was our fourth pregnancy – the other three resulted in miscarriage. To lose him after finally carrying a child to term was devastating.

Not quite two years later, I faced something just as difficult to cope with – putting his newborn sister, Amanda, down in her crib to sleep and walking away. I was terrified that she, too, would leave us; that she, too, would decide that I wasn't a good enough mother and she'd rather be dead than my child. At the time, I believed that of Matt.

You see, when he died, we believed that one creates one's own reality and that spirits choose to be born and at times, choose to die. I believed the spirit that was Matt had needed to be born for some obscure reason, but had decided that 28 days with us (me) was enough to cause him to decide to return to the spirit realm. While I have no wish to offend or to trample on someone's beliefs, this set of doctrine caused untold pain and damage to my spirit and psyche, and I am quite glad I no longer hold that body of beliefs.

The days following Matt's death were horrible. There is no other word for it. Horrible. We were living in extreme Northern Maine at the time, since my husband was in the Air Force and stationed at now-closed Loring Air Force Base. All our family was 2000 miles away in the Deep South. My mother and her companion flew up immediately, and the members of my husband's squadron and their wives came to just be with us, but we still had to deal with the whole thing.

At the airport, I told my mother I had already put Matt's cloths away, and that it shouldn't be impossible for her to be there (she had returned home only a week before after being there to help me with my first baby). She looked at me and said, "You're so strong you make it easier for everyone else." My husband is very quiet, which means that I was the one who had to argue with the funeral home over the coffin – the funeral director kept trying to push a plastic one on us and we insisted upon wood. Many such details consumed me for the next several days as we prepared to fly "home" to bury our son. Having all those things to contend with, and my mother-in-law's insistence upon being the one most greatly bereaved, combined with my dear mother's strength sentence, pushed grief down deeply within me. I was in agony, and yet could not express it.

Every couple of hours, when my engorged breasts would erupt with copious milk flows, the horror of it all would rise up – and some need of the moment would force my feelings away. People say that it's good to be busy, to have something to do those first days, to "get you through." I suppose it is, but not if you never grieve.

That is where I was when Amanda was born – with my feelings wrapped in cotton wadding, packed away where I didn't have to (and couldn't) address them. That is where, to some degree, my feelings remain to this day, though I am seeking healing, finally, after all these years.

Twenty-six Years: Perspectives on Grief...con't

My husband and I suffered in our separate private hells, and perhaps he suffers still. It is a very difficult thing to talk about, grief. But talking about it is exactly what must be done – though we are all different and express grief differently, there are some common elements. And talking through one's feelings, even if only in a journal, is one of those common elements, a step that must be taken in order to heal.

Often, as is the case with me, there are layers of grief, onion-like, which must be peeled back one at a time. Some grief I worked through fairly early – I learned that “forgetting” Matt had died was normal. (Many times, I would startle and gasp, “Where’s the baby? I’ve left the baby,” only to remember that he was gone and be overwhelmed with guilt for being able to forget such a terrible thing.) I worked through the dreadful and dreaded questions from people who did not know he had died, and from those who assume that SIDS is something caused by a parent. I managed to let Amanda sleep in her own crib, though until she was a year old, I was never really free of the panic that would overtake me when feeding her in the night and it would seem that she had stopped breathing.

Years later, I forgave Matt for leaving. Later still, I forgave God for taking him. And later yet, I began to forgive myself. I am still forgiving myself. While I can't say that not a day goes by that I don't think of Matt, I can say that I think of him quite often, that I miss him still, and that I long to see him again. I imagine what he would be like, 26 and handsome, with dark hair and eyes like his father. Intelligent, talented, a musician perhaps. Generous, giving of himself as well as money. Perhaps married, with children of his own. Those images, now, comfort me in some way, though years ago, they would not have.

Perhaps I have fully grieved. Perhaps I have healed. Perhaps 26 years is long enough to be locked in grief. I am not sure. I only know that I will run to him, when we meet again, and greet him with love and with no fear that he will turn from me this time.

Susan's articles have appeared in Mississippi and Parent Life. She is currently enjoying being “Grammy” to 15-month-old Megan, and “Mama” to 24 year-old Amanda, 17-year-old Jonathan, and 16-year-old Betsy.

Day of the Dead

This Mexican holiday is a most interesting look at the roots of Americanized Halloween. Celebrated throughout October, families build decorative ofrendas (altars) in their homes & businesses that are dedicated to ancestors who have died. Decorations include pumpkins, flowers, candy. They believe the souls of the children who have died come back first on October 31st; other ancestors come to visit on November 1 & 2. Gravesites are cleaned & decorated, festivals & meals are shared in graveyards. Some even dress in costumes. It is about more than tricks & treats. And it is an interesting validation of the life-long process of grief & healing. Check out these sites for more information:

<http://www.holidays.net/halloween/muertos.htm>
http://mexconnect.com/mex_/feature/daydeadindex.html
<http://ethnographic.com/event/event.html>
<http://www.dayofthedeath.com/index.html>

Memorials

For Dakota Jones, born & died March 11, 1999 at 4:47 p.m.
For Blake, Katie H's beloved son...
For Isabel, Therese's beloved daughter and first born...
For Nora Elizabeth, Christine's beloved daughter...
For Camille, Richard & Sharon's beloved daughter...
For Joel, Nancy's beloved son...
For Charles, Katie's beloved son...
For William and Wendell, Donnali's beloved twins...
For Micah, Damary's beloved son...
For Allen, Laura's beloved son...
For Amy Dawn, Jen's beloved daughter and first born...
For Cheyenne, Jo's beloved baby girl...
For Matthew, Susan's beloved son...
For Levi, Gail's beloved son...
And for all of our children — who we so dearly miss!

Make a memorial sponsorship of \$10 to this zine, and we'll place a dedication and/or photo in these memorial listings for you. Feel free to call 206-251-6706 or email info@kotapress.com with questions. Send memorial sponsorships to:
A Different Kind of Parenting, c/o KotaPress, PO Box 514, Vashon Island, WA 98070

Submission Guidelines

If you know of a grief resource for parents, a quote that inspires you on those dark, painful nights, or have a one page article about grief & healing, or a short poem you've written in memory of your child, write to us. We'd like to hear from you. Send your work via email—cut and paste directly into the email, please. No attachments will be opened. Include a few lines of a bio along with your submission, too. And in the subject line of you're your email, please type, "Different Kind of Parenting Submission."

Email: info@kotapress.com URL: www.KotaPress.com Phone: 206-251-6706

Subscription Information

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Send subscription requests to:

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PO Box 514
Vashon Island, WA 98070

KotaPress Mission Statement

This press was started as a safe haven where we could publish our grief and healing artworks. Since its inception, KotaPress has extended this safe haven to other bereaved parents, artists, and poets around the world. We aim to continue offering a home for artworks created by artists who are on a healing path regardless of the tragedy that put them on the path in the first place.

KotaPress Objectives

We offer both print and electronic media for the display and sale of these artworks. These media include the www.KotaPress.com, a website outreach offering monthly online Loss, Poetry & Art Journals; the Loss Journal houses "The Dictionary of Loss," Articles, Grief Support Links, and SeattleM.I.S.S. information; an eStore where we retail books, cds, art, and classes.

Our print outreach includes the quarterly 'zine A Different Kind of Parenting: For Parents Whose Children Have died; The Mrs. Duck Project providing free e-copies of the grief support book Mrs. Duck and The Woman to bereaved families around the world; and many print books such as Flash Of Life, Father Son Holy Ghost, Unforeseen, Complexions, Tiny Hands and more.

Additionally, we offer one-on-one sessions to individuals seeking healing or creative consults. Session are offered in person at our Vashon Island location, via email, or your location when travel expense provisions are considered. We offer Poetry Therapy, BodyWrites!, Expanding Poetry, Self-Publishing Made Easy, Guerilla Bookmaking workshops, and custom consults for clients wishing to publish books that in some way focus on grief and healing.

KotaPress PO Box 514, Vashon Island, WA 98070 www.KotaPress.com

**You will always be a parent.
Nothing, not even death can change that.
-Nanna Memoo
Dakota's Grandma**

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PO Box 514
Vashon Island, WA 98070

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