

Helping Hands

Helping After Neonatal Death

Winter 1999

Surviving the Holidays

Finding Treasure Amidst the Ruins

By *Jonna Clark*

As the holiday season brings its attendant joys and traditions and the usual frenzy of plans and preparations, our family faces a special situation.

One year ago on Thanksgiving Day, our beautiful third son, Ethan, died, joining a growing number of children taken by Sudden Infant Death Syndrome (SIDS). During the holidays, it is customary to take stock, count our blessings and be thankful for all we have been given. For those of us who have lost a child, giving thanks can be difficult.

For no matter how much we have, materially or economically, no matter how gifted spiritually, physically or intellectually, no matter how many other children we may have, none of these can fill the void left by our lost child.

This year in the aftermath of losing Ethan, we have experienced great lows and yes, even highs. We have learned much about the valley of the shadow and what it means to take the walk in the dark that is grief. We have changed, each in our own way, as we continue to live with, and try to process what Ethan's passing has meant. We have questioned much and scrutinized that which most take for granted. We continue to miss him, and his place in our family and our hearts remains unfilled.

Yet even in our year of upheaval, pain and struggle, we have found good. Amidst the confusion and anger, there have been positives that stand out. And there have been things to be thankful for.

Slowing to look in the mirror

Had it not been for Ethan's death, I might never have stopped my hectic pace and constant pressing onward long enough to ask who, where, what and why.

“God whispers to us in our pleasures, speaks in our conscience, but shouts in our pains; it is His megaphone to rouse a deaf world.”

C.S. Lewis in “The Problem of Pain..”

Grief slowed me to the point where I could begin to ask myself some hard questions. I became more certain of who I was, where I was going and to whom I belonged, as my faith and dependency on God became ever more important in just getting me through each day.

C.S. Lewis wrote in “The Problem of Pain,” about the awakening that can come from loss. “God whispers to us in our pleasures, speaks in our conscience, but shouts in our pains; it is his

megaphone to rouse a deaf world.”

Ethan became the little trumpet player in our lives, as his death brought us to our senses and to our knees.

Letting go of the insignificant

With the overwhelming grief that immediately enveloped our lives, we soon found much we had deemed important before, no longer was. It seemed as though the fires of mourning burned off all that was not necessary.

I stopped worrying about whether the Christmas wrapping paper matched our living room decor perfectly, and whether the presents had been arranged artfully under the tree.

I decided I never cared to see the insides of a crowded, noisy, overdone shopping mall again and bought all but the children's gifts at a local craft show. I let go of expecting myself to bake and decorate and entertain.

We gave ourselves permission to be only with people who acknowledged our grief and accepted us the way we were. Ethan's death seemed so large, so all-encompassing, that letting go of the trivial was like second nature.

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A Letter From HAND

Time doesn't erase parents' need to remember child

Ten and a half years ago, our first born decided to arrive a little early on June 18, 1989 — Father's Day. He suffocated during the delivery and was revived. He lived seven precious days and died in my arms. I quickly became pregnant and spent the holidays on bed rest.

I sewed Christmas ornaments with his name and birthday on them, and asked my husband to plant a tree outside my window so I could watch it grow. Holidays in general were not fun nor exciting and it was very hard to watch others enjoy them. Then I would thank God that they weren't experiencing the pain that I was.

Creating a blanket that was a memorial to my son gave me some solace. My family still uses it and it will be our family heirloom. I want every year to include memories of him. Five years after my son's death, my family felt they needed to back away and not be involved. They felt ready to move on.

During the holidays, I remember my son by including my three subsequent children in activities like visiting the cemetery where we decorate and arrange his special toys on his grave. As we decorate the tree, we admire each ornament I made in his memory and we wonder out loud what he would be like had he lived.

Now, ten years later, I find myself volunteering for church activities for children in my son's age group and feeling pride and peace in knowing the things that he may have been interested in and done. It also comforts me to know in my heart that I will see him again.

I want to let other grieving parents know that with time they will find ways to remember the child they lost and still find joy during the holidays. They will also discover that the holidays mean more to their spirit than ever.

Erin Osai
Boardmember, Hand of the Peninsula
Mother of Eplahame Jagger Osai June 18-25, 1989
Alyssa Osai April 28, 1990
Kali Osai January 2, 1993
Rosemarie February 1, 1996

Helping After Neonatal Death

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Helping Hands

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When Someone You Love Has Died

By Judi Tatelbaum, M.S.W.

We may need extra help surviving the holiday season if we are in the midst of grief. Following are a number of survival strategies. Using these suggestions won't necessarily take your grief away, but they can help you manage your grief at a time of the year when the world is supposed to be joyous.

Be kind to yourself

This is a time when it is important to take good care of yourself. Nothing you do will make a bigger difference than respecting yourself, your needs and your feelings. Handling your emotions may be the only job you can manage right now. Because no one knows your needs as well as you do, you need to notice them and honor them. Don't overwhelm yourself just because it is the holiday season. Instead, do only as much as you can comfortably manage. Get the rest and nourishment and affection you need. Choose what's best for you — to be with people or to spend time alone, to be immersed in the holiday spirit or not.

Express your feelings

The surest road through grief is to feel it, not deny it. If you are hurting, the best advice is to allow your feelings. Cry if you need to cry, rage if you need to rage. Admit the longings, the loneliness or whatever you are feeling. Don't suppress yourself. Feelings expressed ultimately disappear, but when you suppress yourself, nothing changes.

Ask for what you need

Other people do not know how you feel unless you tell them. Don't just go along with people or plans that are not for you.

Tell people what would help you most. Speak up!

Friends and relatives may think you will feel better if you do not talk about your loss, or they may be afraid to upset you by mentioning the missing person. If you want to talk about the person who is gone, say so. If you want your privacy respected, if you need companionship or if you want a shoulder to cry on, say so. People outside your grief may feel awkward and not know what to do. As much as they want to help, they need you to direct them.

Don't be afraid to ask for help with planning, shopping, entertaining or just getting through today. As hard as it may be to ask, force yourself. Ultimately, asking will make your life a little easier. If you cannot shop or decorate this year, ask a friend, relative, hospice or other social agency volunteer to help. What looks arduous to you, may be a lot of fun for someone else. As hard as it may be to imagine, remember that serving you can be very satisfying and rewarding for the other person.

Create support for yourself

Sharing your pain eases it. Be sure you have people with whom you can talk. Most of us can cope best with tough times if we have a loving presence — a relative or friend to walk with us through this painful time. When spouses or family members hurt as much as you do and cannot be a support, find an alternative. Look for a short-term support partner, perhaps a friend, another person in grief, a relative, a counselor. Or, create a small group of people who have similar

concerns with whom you can stay in touch daily or frequently through the holidays or beyond. Support people and support groups really help.

Help others in need

Contributing to someone else gets your attention off yourself. Helping another can be a very effective way of healing after a loss, because when you are immersed in someone else's needs, you can be free of your own distress and pain. If you have the energy, there are many people who need you. Some possibilities are to volunteer to be with older folks or children, to help in a hospital or a soup kitchen, or to help a friend in need over the holidays.

Appreciate your loved ones

Enjoy the people you love. It is natural to feel alone in your grief and to want to isolate yourself, yet that closes off all chances for closeness and nourishment from other people. Don't deprive your children, your spouse, other loved ones or yourself. As hard as it may be to get your attention off your loss, they need your love too. And in return, their love can nourish you and help you begin to heal.

Avoid comparisons

Feeling jealous of intact families and feeling deprived are natural reactions after a loss — as if other families are happier than yours, as if other people have what you do not. We have a lot of illusions about how other people live. Actually, for many intact families. Reunions can be stress-

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ful and upsetting. Contrary to our illusions, holiday times are often not ideal times for families, intact or not. Don't try to compare lives, it only adds to your misery. Embracing what you have gives you much more power than regretting what is missing.

Resolving how or where to spend the holidays

Choosing how or where to spend the holidays may be your biggest dilemma. There is no perfect solution. Holiday time may be hard no matter what you do or where you are. In fact, it may seem as if you are trying to pick the best from some rotten alternatives. The choices: celebrate as usual, avoid the holidays altogether, or do something brand new.

Celebrating as usual

Many people wish to keep their holiday traditions intact, to celebrate as usual. This way is bound to be painful, accentuating the gap left by the loss. It is fine to follow family traditions as long as you know they cannot be the same as before your loved one died. Pretending you can recreate the past will only cause you more grief. Just remember to allow any feelings as they occur. If you have the energy to do so, following old traditions may enhance your self esteem and may help you manage the holidays successfully.

Avoiding the holidays

It is not wrong to want to avoid Christmas or other holidays entirely. If celebrating seems too difficult to bear, you can choose not to observe the holidays and go somewhere else -- skiing, a cruise, a resort, a different city. If you cannot afford to travel, go to the zoo or the movies or some

other distracting place. There is no guarantee that this will erase your pain, but it may lessen it some.

Doing something new and different

If NOT celebrating would deeply disappoint or deprive children or other family members, you probably cannot run away from Thanksgiving or Christmas. Yet, you can avoid repeating your traditional ways and perhaps observe your holiday more simply than before. People often work too hard cooking, decorating, planning, shopping and entertaining at holiday times, so you can at least ease up.

Often, the more we try to recreate the past, the more obvious is our loss, so changing traditions can be a freeing and satisfying way to spend the season. You can celebrate Thanksgiving, Hanukkah or Christmas in a brand new way by going to the home of a different relative or friend, having a family reunion away from home, or eating in a restaurant. You can do anything that will make your holiday experience new rather than a memory with someone in it missing.

If it is too hard for you, personally, to think up a new way to do the holidays, give the job of planning to a creative friend or relative. Again, most important in taking care of yourself is not to feel you have to do it all -- whatever the circumstances.

You'll survive the holidays

You may hurt, but you will survive. The holidays may be the worst of your grief time. Eventually, you will heal, and your memories will persist without pain. Meanwhile, it's OK not to have a good time. There may be no way you can make this holiday fun and nothing you want to

do. Allow that you may not enjoy the parties, reunions and events of the season. If you are hurting and unable or unwilling to have your attention on anything else, let yourself be. It is also OK to have a good time, even though you have experienced a loss. You do not have to deny pleasure to yourself or your family. While grieving, we often feel guilty about having fun, as if we should be miserable all twenty-four hours of a day. That is not necessary. Often, we think it is how much we grieve that signifies how much we care about the one who died. Not true! Our love is not measured by the extent of our grief. We can love forever without having grief as our testimonial to that love. Remember, few of us would want others to be forever bereft because we were gone.

Perhaps the best testimonial we can give to our missing loved ones is how we live our lives. Don't deny yourself life because someone has died. If you can do so, enjoy the holidays and every day; for death teaches us, more than anything, that every day of life is precious and worth living to the fullest. The best gift we can give ourselves and others for the holidays and every day is to live our lives wholeheartedly.

*From Bereavement Magazine
November-December 1991*

Special Thanks

To Gina and Blair Glenn, for opening their house to host a very successful HAND of Santa Clara County Volunteer Celebration Picnic in September.

Nearly 40 people attended, renewed friendships, and celebrated the many contributions of our volunteers over the past year.

Support Meetings

Support meetings are informal gatherings where parents can receive and give support by sharing common experiences as we work through and resolve our loss. We cordially invite you to attend.

Meetings may start out with a topic of discussion, but everyone is free to bring up any questions or aspects of their loss which may concern them.

Attending your first meeting does take courage, but parents who attend find a comforting network of support, encouragement, friendship and understanding.

Nothing is required of you. There are no dues or fees. You need not speak one word. Even if you no longer need the meetings for yourself, come and share your experiences with someone who has recently suffered a loss.

HAND of Santa Clara County

Support meetings are held on the first and third Thursdays of the month.

Time: 7:30- 9:30 PM

Dates: Nov. 4 and 18
Dec. 2 and 16
Jan. 6 and 20
Feb. 3 and 17
March 2 and 16

Facilitators: Nadine, Sherri, Carmen, Ellen, and Susan.

Location: Our Savior's Church, downstairs library, 1224 N. Winchester Ave., Santa Clara (between Pruneridge and Scott).

HAND of the Peninsula

Support meetings are held on the first and third Wednesday of the month.

Time: 7:30-9:30 PM

Dates: Nov. 3 and 17
Dec. 1 and 15

Jan. 5 and 19
Feb. 2 and 16
March 1 and 15

Contact: Celia Hartnett

Location: Sequoia Health and Wellness Services, 702 Marshall St., Redwood City. Call (650) 367-6993 for information.

HAND of Santa Cruz County

Support meetings are held on the third Wednesday of the month.

Time: 7:30-9:30 PM

Dates: Nov. 17
Dec. 15
Jan. 19
Feb. 16
March 15

Facilitators: Linda Coker
(831) 338-6864

Lisa Jones
(831) 475-4188

Location: Congregational Church of Soquel

HAND of So. Alameda County

Meetings are currently being held on the first and third Wednesday of each month.

Time: 7-9 PM

Dates: Nov. 3 and 17
Dec. 1 and 15
Jan. 5 and 19
Feb. 2 and 16
March 1 and 15

Location: Washington Hospital, West 2500 Mowry Ave., Health Education Library, third floor.

For more information, please call 1-800-963-7070 and ask for HAND

Families seeking information on bereavement meetings in **Pleasanton** should call 925-373-4114 and ask for HAND.

Pregnancy Support Meetings

Parents who are pregnant again after a loss have special emotional and psychological needs. Pregnancy Support Group meetings address the concerns of bereaved parents who have started or are thinking about starting another pregnancy. Fathers are especially encouraged to attend.

HAND of Santa Clara County

Pregnancy support meetings are held the second Thursday of the month on an RSVP basis. If you wish to attend, please contact Gina (408) 868-9605 or Kathy (408) 848-1716.

Time: 7-9 PM

Dates: Nov. 11
Dec. 9
Jan. 13
Feb. 10
March 9

Location: Prince of Peace Lutheran Church, 12770 Saratoga Ave., Saratoga, conference room off of the sanctuary.

HAND of the Peninsula

Subsequent pregnancy support meetings are on the second Wednesday of every month at 7:30 p.m. Anyone wishing to attend a subsequent pregnancy meeting may call Celia Hartnett at (650) 367-6993.

HAND of So. Alameda County

Subsequent pregnancy support meetings are being held as needed. Anyone wishing to attend a subsequent pregnancy meeting may call (800) 963-7070 and ask for HAND.

Donations

Our warmest thanks to those who have sent donations to HAND. It is through your support that HAND is able to grow and help others.

Marilyn Sponza-Swartz, in memory of Julia Vechione Sponza.

Karen Adams, in memory of Lesley Melissa Vaughan.

Ann & Piero Pianetta, in memory of Roberto Carlo Pianetta.

Mari Lou and Toru Hagiwara, in memory of Baby Hagiwara.

Alana & Robert Lee, in memory of Kyle Robert Lee.

Craig and Anne Stenehjem, in memory of Hayley Anne Stenehjem.

Ken & Carmen Banuelos, in memory of Vincent Elias Banuelos.

John and Karen Carroll, in memory of Justina Maxime Rose Carroll.

Tony & Marianne Bullock, in memory of Ryan Joseph Bullock.

Jim and Katherine Keaney, in memory of Dane Lyle Keaney.

Cherisse White, in memory of Montana Lafayette White.

Peter & Lori Williamson, in memory of Shelby Hemenway Williamson.

Margoth Mendoza, in memory of Stephen Prosen-Mendoza.

Craig and Julie Pampeyan, in memory of Emily Ann Pampeyan.

Laura and Tony Zielonka, in memory of Zachary Curran Zielonka and Kristen Nicole Werthman.

BioStar, Inc. in honor of Heidi Olson for her significant contribution in the fight against Group B Strep and in memory of her son, Jacob.

Paul & Belinda Spallas, in memory of Lauren Marie Spallas.

Sherri and Robert Penny, in memory of Megan Valerie Penny & Erin Arielle Penny;

Janell and John White, in memory of Jacklyn Mae White.

Mary Ludwick, in memory of Tyler Jones Ludwick.

Douglas and Diane Ganser, in memory of Emily Jane Baker.

Lisa McLean, in memory of The McLean Girls.

LeAnn and Steve Crawley, in memory of Keegan Robert Crawley.

Karen Goodwin, in memory of Leanne Goodwin.

Kent and Kimberly Grubaugh, in memory of Jenna Nicole Grubaugh.

Michelle and David Finnegan, in memory of Jack Finnegan.

Kathryn Shugart, in memory of Ryce Shugart Civjan.

Robertta Blake-Marietta, in memory of Hallie Sarah and Baby Marietta.

Nina and Thomas Suydam, in memory of Danielle Nicole Suydam.

Elise and Paul Donovan, in memory of Alexandra, Isaiah, Anthony, and Isabella Donovan

Jose and Jocelyn Leano, Jessica and Jacqueline in memory of Joseph Jonathan Leano on his third birthday.

Emily Corpos, in memory of Maria's 24th birthday.

Caryn and Richard Goldman in memory of Sasha's 8th death date.

Jay and Anna Shah, in memory of their niece, Tara Maria Cherrian Borchers.

Kathryn & Steven Wahl.

Ivy Gray, in memory of her great granddaughter, Talia Elise Nelson Twicken.

Cherie and Marc Marcus, in memory of Baby Sarah Marie and in thanksgiving of Gabriel Emmanuel Marcus.

Donations to Human Race: Jill Nelson and Joe Twicken

Continuing thanks to Sequoia Health & Wellness Services and the INNW for their support.

HAND Parent offers service in memory of her son

Sharyn Fowler has come up with a way to help HAND parents and remember her son, William Richard Fowler Jr., who died in 1976.

At no charge, Fowler will create an electronic neonatal death announcement by scanning a photo or sonogram and emailing it with the parents' message to family and friends. She will create a printed announcement and mail it if you send her postage, envelopes and an address list.

For more information, contact Fowler at Sharyn@webellah.com

Births

Jonathan Everett, David Jansen and Carissa Rebekah, June 16, 1999 to Desiree and Bill Black.

Matthew Joseph, Aug. 13, 1999, to Susan and Ray Hoppe.

Matthew Christopher, Sept. 10, 1999, to Kristie Schulman.

Lucas, Aug. 26, 1999, to Patti Leeper and Craig Ball.

Inservices

Nov. 11 — Celia Hartnett, Jill Nelson and Joe Twicken — South San Mateo County Police Department. Chaplain's Association on SIDS.

Treasure *continued from page 1*

It has been refreshing and freeing to shrug off the unimportant details. As we heal, we strive to keep ourselves from sinking back into caring more about how things look than how things really are.

Living the moment simply

Ethan's death has taught us much, but one of the most satisfying lessons has been one of contentment, of living in the moment and understanding that in life there are no guarantees. I have learned to appreciate the *now*.

With Ethan's brothers, in my home, at my computer or gar-

dening, I have become satisfied and settled in a new way. Before Ethan's death, I was rushing forward constantly to the next activity, purchase, phase or place. I never fully enjoyed the present, so hurried was I to get on with life.

Before Ethan died, I never could have spent an afternoon in my garden pulling weeds and tending the flowers, I needed to be ever on the run. Books were to be read at one sitting, dinners to be rushed through and tomorrow and the next day anticipated to the point where I missed today.

Thankfully, I never will live that way again. While I never will be thankful for Ethan's death, and

continue to want to learn more to join the fight against AIDS, I can't help but be glad for all we have taken from this abject tragedy. I have given up worrying as a pastime and now know that just wishing for something will never make it true.

Corrie Ten Boom, the woman who survived a Nazi death camp after sheltering Jews in her home during World War II, once told a congregation that we must hold things loosely in life, for then it does not hurt as much when we have to let go, and God does not have to pry our fingers from around that which we are holding. I strive for a lighter, looser grip on life and those I care for, while remembering Ethan and all his death has taught us.

A Holiday Message

Special Handling, Please

*I was handed a package the other day.
It was wrapped securely to be mailed away.
Attached to the outside as plain as could be.
Was a simple note for all to see:*

*Please rush through the holiday season;
Too painful to open for any reason!
Contained within, find one bereaved heart --
Fragile, broken, falling apart.*

*Tried to go shopping the other day;
They hype of the season blew me away.
Sat down to write cards,
That was insane.*

*Couldn't find the list
Or think of my name.
People say, "Come over,"
"Be good cheer."
"Celebrate the holidays."
"Prepare the New Year."*

*But my grief overwhelms me
Like waves in the sea.
Can they cope with my crying;
An unsettled me?*

I don't have any holiday cheer,

*Decorations, traditions, big family meal,
I can't do it this year.
Do you know how I feel?*

*Guilty and frustrated!
I've let everyone down!
Our holiday celebrations
Used to be the best in town!*

*So just ship me away
Address unknown
When my grief is over,
I might fly home.*

Signed: Bereaved Heart

**I just couldn't send Bereaved Heart away,
so I jotted a note and left it that day:**

*Dear Bereaved Heart:
the death of your loved one
Has forced you to start
A new type of living
That's hard on the heart.*

*Undecorating your life
Of its angers and fears
Is not easy to do*

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Special Handling *continued from page 7*

*And undying your guilt
Can release a bundle of strife.
Questions are stirred up
About living and life.*

*Don't be concerned now
With invitations, big meals
See how the little stuff
Handles and feels.*

*Let the love of your family,
Neighbors or friends
Uphold and sustain you
When you're at loose ends.*

*Most are eager to be there,
Willing to share.
Tell them your needs,
And they'll show you they care.*

*They'll take you shopping,
Write cards, even cook.
Let that stuff go now
Get yourself off the hook.*

*You need time for healing,
You've much work to do.*

*Your heart needs mending--
Give that gift to YOU.*

*Take a walk, read a book,
Try something your style
Make sure it's relaxing,
Makes you pause, rest awhile.*

*When holiday invitations
Knock at your door,
Don't say "yes" to five
When you only want four.
If you wish to remember
Your loved one who died,
Plant a tree, give a gift
Let your heart be your guide.*

*This season of wonder
Can bring you relief
If you're willing to unwrap
Your tears and your grief.*

*Please listen, Bereaved Heart,
Stay close and please dare
To open your package
And let others care.*

Signed, C.U. Soon
From Bereavement Magazine
November-December 1990