

BABIES REMEMBERED

HONORING AND REMEMBERING LOVED BABIES WHO HAVE DIED

VOLUME: 1 ISSUE: 2 JUNE/JULY 2009

Giving and Receiving Support

This issue on support promotes many types of support. After a baby dies (or even after other types of tragedies), the need is great for most people to speak with others who understand, people who can, "Finish your sentences for you, because they have been there." Bereaved parents feel alone, in shock, as if they are going 'crazy,' and are unaware of what is to come and how to deal with such a serious crisis. Connecting with others can be one of the most helpful things to do.

In fact, Dr. Glen Davidson in his study and subsequent book, *Understanding Mourning*, indicates that finding support is at the top of the list of needs that bereaved people have; in fact, it comes before eating nutritious food, drinking water and non-caffeinated beverages, and sleeping. He notes the high death rate in widowers in the first year following their partner's death, if they don't find support.

What does finding support do for families?

- Gives hope, that others have been through it and survived
- Gains an 'extended friend/family network' (often new lifelong friends are made)
- Feels less alone
- Learns practical tips and coping strategies
- Gives a chance to 'do' something, not just ignore or wallow at home alone
- Learns more about resources from participants and the leader
- Offers a chance to give back by supporting others who come after
- Helps prepare for what is to come
- Gives an opportunity to give to others, not just receive
- Helps make meaning of their own baby's short life and death

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Couples Retreat at Faith's Lodge

Six amazing couples joined Tim Nelson and me for a Mother's Day weekend retreat at Faith's Lodge. Lest you haven't heard of this special place, allow me to introduce you to it. Susan and Marc Lacek, parents from Minnesota, created this retreat center in the Wisconsin woods (90 minutes from Minneapolis) to honor their daughter Faith who was stillborn and to offer up help and support to families in crisis and those who have had a baby die. The cost to families is minimal (\$25 donation per night) and the beauty and serenity of it is priceless. www.faithslodge.org

First Candle (www.firstcandle.org) teamed up with Faith's Lodge and Tim and I to use this weekend as a chance to pamper couples (massage, free lodging and meals, memory making time, campfire, group sessions we led, walks in the woods, and more.) Half of the couples had a baby die of SIDS or SUID and the others had a



Faith's Lodge is a unique retreat for families who currently have a seriously ill child or have suffered the loss of a child. Located on 80 picturesque acres in the Northwoods of Wisconsin, Faith's Lodge has eight individually

designed guest suites that can each accommodate up to six people. Two suites adjoin to accommodate larger families and are handicapped accessible. www.faithslodge.org

stillborn or a baby who lived a very short time. We focused on Couple Communication (each couple received a free copy of our new book) and had some very funny moments and some serious ones, too. The couples commented afterwards that they were so grateful to have come. They found growth, humor, shared sadness, and hope from their special 'escape' to Faith's Lodge.

A special thanks to— First Candle and Baby SafeUSA who made it possible so these couples could have a memorable first Mother's Day after their baby's death. And to Faith's Lodge and their wonderful staff who made everyone feel so welcome. Tim and I had a most blessed time with these delightful couples, and we can't wait to do it again!



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Sherokee Ilse: The author of *Empty Arms*, 17 books/pamphlets dealing with grief and loss, and the newsletter 'Babies Remembered'. I have been helping both parents and professionals in the field of stillbirth and infant loss, as well as promoting research on probable causes for stillbirth to save babies lives, for over 27 years. I am a bereaved mother first and a professional second. Feel free to contact me re: speaking, my books, the new CEU Units I am developing or other information at www.babiesremembered.org or by phone at 952-476-1303.

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What types of support are often available?

Many, though not all, communities have a support group. Support groups may be run by parents or by professionals—usually a nurse, social worker, chaplain, or counselor. They may be structured in different ways, from an open group with no topics that promotes mostly storytelling (with guidance from the leader), an open group with different topics each week, yet still allowing for parent stories, or a closed group with topics and some sharing. Hospitals should give out information about any groups within a few hours range of the hospital so that parents do not have to go search for groups.

Peer Support is becoming more popular in communities. Sometimes the Peer Support Parent has been through training and sometimes not. More and more hospitals are asking bereaved parents at the time of their loss if they would like someone to come or call right away. This can be helpful as parents are faced with decisions they have no experience with, such as seeing, holding, and bathing their new baby who has died. Or the Peer Support connects up sometime after parents go home. Whether the hospital has the Peer Support Parents in their volunteer pool, they are connected to a community resource, or they are individuals who simply offer to be available, helping to connect people up is important. Utilizing churches, synagogues, neighbors, and even co-workers to find people who have also had such a loss and are willing to help, is something that can be done. Peer Support Parents are a vital resource every community should have. (*See the box *Giving Birth to Death*.)

Books can be of support at the time and over time. *Empty Arms. When Hello Means Goodbye. The SIDS Survival Guide. A Guide for Fathers* (all available from www.babiesremembered.org) or the many others available at Amazon.com are important resources which can be read and reread in the privacy of one's bedroom, living room, or while sitting outside absorbing some healthy sun.

Websites are another commonly used method of support. There are so many sources here that I hesitate to even offer up a list. *Facebook* and *MySpace* have many groups and discussions. At the end of my website (www.babiesremembered.org), and on many other websites), you will find a 'Links or Resources' section that can open the portals to a world of other sites. It is amazing how much time some people spend exploring and chatting on the web. This is also a way to search for specific topics, books, memorial items, research, and so much more.

What can caregivers do to help families have more support?

- Determine if there are enough groups in your area. If not, start one. Then ask staff who interact with bereaved families to help facilitate the group (or at least attend a minimum of 3-4). This will give the leader some support and will help the staff member see the ongoing needs, growth, and struggles of families beyond the acute setting.
- Make sure books and materials are given out to families at the time of their loss (not just a few pamphlets or copied handouts, which gives parents the impression their baby's life is only worth a few pieces of paper...words I hear all the time from parents.) Also give out lists of resources that are complete so they know where to find them.
- Offer Peer Support Parents and explain why this can be so helpful.
- Most of all, do not assume such things as: They are, "Overwhelmed," or "Have enough family around them," or "Can't possibly read that now," or "Won't want to talk with a stranger so soon," or "Aren't too upset, therefore don't need what others might need." Instead, explain all the options and WHY. When most people understand the 'why' behind it and that other parents who have been through it keep telling you to do these hard things in order to make good decisions and to minimize future regrets, they may listen and be more open, despite their misgivings.

The Listener

Those of us who have traveled a while along this path called grief, need to stop and remember that mile, the first mile of no relief

It wasn't the person with answers who told us the ways to deal it wasn't the one who talked and talked that helped us to start to heal

Think of the friend who quietly sat and held our hands in theirs, the ones who let us talk and talk and hugged away our tears

We need to always remember That more than the words we speak its the gift of someone who listens that most of us desperately seek.

Nancy Myerholts
(Compassionate Friends, Central Iowa Chapter)

Peer Support Training and Upcoming Event

I have been conducting training on this topic for the past 27 years, actually doing quite a bit lately, especially phone/computer training with First Candle www.firstcandle.org. I am presently working with Jeff Hunsberger of The Simon Project to offer a 2-day Peer Training in Berlin, Vermont, Sat.-Sun. October 10-11, 2009. Anyone who works for an organization that does peer support, or who wants to start a local Peer Support Program, or peer support parents (previously trained or not) are invited to attend. This is intended to be a pilot program and a collaborative opportunity with other groups who do this work. E-mail me if you wish to learn more. sherokeelse@yahoo.com

To hear a short audio I did on Peer Support Training and First Candle visit www.babiesremembered.org.

* *Giving Birth to Death*, Suzanne Pullen. Among other things, this study shows that 75% (379 respondents) wish they could have talked to someone who had the same diagnosis in the days after they found out.' And 71% (359) said it would have been helpful if the person who delivered the diagnosis had given them a peer support contact. Email author Suzanne Pullen if you wish to see the full study. lifefterstillbirth@yahoo.com

Support Group Survey Summary

Over the past 6 months, I have conducted a support group survey to determine the 'state' of support groups—if support groups are still relevant and what are the turnouts at meetings (and if good, what factors contribute to that.) So far, the number of support group leaders who responded is 75. Please feel free to invite other support group leaders to take the survey. It would be nice to have hundreds of responses. Also, be sure to tell them to put in their email address so we can list the group and send the results. http://www.surveymonkey.com/s.aspx?sm=ei6D2p7mN2_2bm9TK3lezHaw_3d_3d

Preliminary conclusions: It seems that most groups include bereaved parents as leaders or co-leaders of the group. What makes a group work, grow, and continue? A common thread seems to be building relationships, especially beginning at the hospital where a personal invitation to attend the group can be given. Reaching out to families to invite and remind them adds another dimension of relationship-building. In addition, professional leaders or parents from the group often contact newly bereaved or regular participants prior to the group meeting. Parents probably attend the group for themselves, as well as to see their group leader again (and probably other group participants).

Most groups meet monthly (79%) and most have parent events such as Memorial Services (74.3%), Walks to Remember (36%), and Holiday Programs (42.9%). Quite a few have fundraisers (50%). This extra involvement

connects people together and builds community, in addition to honoring their babies and giving them something positive to do.

Other support groups make quilt squares, do plantings during celebration of life, eat out together, have a balloon or butterfly release, organize volunteer activities for members, invite speakers, have a three month follow-up after their loss which then becomes another opportunity to invite them to the group, an annual spring social, offer financial assistance and take food to people in need. A few leaders mentioned that they network heavily with ob-gyn docs and clinics and other community groups.

It was interesting to note that a number of groups make things at their meetings – scrapbooking, jewelry, wood working, etc. And some leaders even bake their own goodies to bring, offering that personal touch. The most common style of group is the 'open sharing, no topics (56%) and then 'open sharing, organized around topics each meeting' (33%).

Most who have med-high attendance make calls or send emails prior to each meeting. Some send cards and notes to check in and mention the group there or have newsletters. Approximately 71% of the groups have 6-25+ attendees on average. And 59% consider support group participation as strong, while 56% of groups have been going for 11 years or more.

(Continued on page 4)

People and Groups Who Help



Helping After Neonatal Death, is a California non-profit 501(c)3 corporation, founded in 1981 to help parents, their families and their healthcare providers cope with the loss of a baby before, during, or after birth.

HAND is a resource network of parents, professionals, and supportive volunteers that offers a variety of services throughout Northern California and the Central Valley. There are no fees for services. HAND relies entirely on donations to support its programs. www.handonline.org



The mission of **Share Pregnancy and Infant Loss Support, Inc.**, a 501(C)3 founded in the late 70's, serves those touched by the tragic death of a baby through early pregnancy loss, stillbirth, or in the first few months of life. www.nationalshare.org



The MISS Foundation is a 501 (c) 3, volunteer based organization committed to providing crisis support and long term aid to families after the death of a child from any cause. MISS also participates in legislative and advocacy issues, community engagement and volunteerism, and culturally competent, multidisciplinary, education opportunities. www.missfoundation.org



SANDS, Promotes awareness and understanding following the death of a baby from conception through infancy. Newsletters, provides links to regional support groups, offers support, training, and resources.

Australia: www.sands.org.au
New Zealand: www.sands.org.nz
UK: www.uk-sands.org

Support Group Survey Results

The group primarily serves:

- 89% Parents with an infant loss including miscarriage
- 9% Parents with an infant loss excluding miscarriage
- 39% Parents who had a baby die of SIDS
- 46% Fathers
- 43% Parents who have ended a pregnancy
- 13% Parents whose child has died, any age

How long has it run:

- 5% one year
- 21% 2-5 years
- 15% 6-10 years
- 20% 11-19 years
- 36% 20+ years

On average, how many people attend:

- 26% Less than 5
- 63% 6-15
- 8% 16-24
- 2% 25+

How often does group meet:

- 8% weekly
- 65% monthly
- 15% bi-monthly
- 9% Other

What style of group meeting:

- 56% Open sharing, no topics
- 33% Open sharing, organized topics each meeting
- 10% Closed (eg. 6-8 week sessions)

What do you do to keep your attendance up:

- 39% emails to remind
- 36% Notes/letters to remind
- 28% Phone calls to remind prior to each meeting
- 28% Organize events to involve parents
- 26% Involve parent members in reaching out
- 18% Reminder in local paper, churches, etc.
- 15% Nothing
- 12% Make things during meetings (scrapbook, woodworking, gifts, memory items, etc.)
- 10% Bring baked goods

Other events organized with/for families:

- 36% Walks to Remember
- 74% Memorial Services
- 50% Fundraising events
- 36% Meetings
- 29% Trainings
- 24% Peer Support programs
- 43% Holiday Programs



Background: Over the past few years, a number of people have approached me concerned that many support groups have closed, attendance is down, and they feared that more might close. As I spoke to others, however, I found that there are many groups who still have a steady, if not excellent, attendance record. What helps a group thrive, I wondered.

About the survey: Using Survey Monkey, I asked 10 questions about support groups. The word went out over the internet and via emails and then spread from there.

In addition to the statistics, which might help you in your group or if you are contemplating starting or closing a group, the answers were very interesting. While helpful, it is clear that more work needs to be done in examining the support group issue.

Respondents: Mostly from US and then the UK, New Zealand, Australia, and Norway. Many of the leaders were bereaved parents (34 of 75), or a combination of professional and bereaved parents (44), with some actually being both a bereaved parent and a professional. There were 14 nurses, 12 social worker/psychologists, 5 chaplains, and a couple of 'others' who led groups.

A few comments that were shared: Caprice Bass – MISS Foundation, Denver - At MISS, "We discuss holiday grief in November and share a packet with examples of holiday letters other parents have written. At the December meeting we make fleece tied blankets to donate to local hospitals. Anyone who wants to deliver these can. If not, we (my co-facilitator and I) deliver them. People seem to want to do something in memory/honor of their baby at this time of year, so this has been a success for us, usually the biggest meeting of the year.

A NYC group leader noted, "I believe that charging a nominal fee, \$50 per participant, to reserve a place in the

group helps, but previously organized vacations and professional conflicts from both parents often cause lapses in attendance."

"We foster a spirit of caring for one another and consistent attendance is one of those ways we tend to one another." Kindermourn in NC meets weekly.

The leader from the Rockford IL, Healing Hearts wrote, "For those who need the support group, it is available. We believe that death still remains to be a very private situation and belief, and that is why the support groups remain so small. We have serviced many families over the years even though the groups are not large. It is not the size of the group but the quality of the work that we are doing in the community. Many times our 'single family' work is the most important that we do because it has immediate impact and it remains very meaningful."

Karen Frazier, who has excellent attendance at her Tampa Bay group states, "We have a lending library, make phone calls to talk with parents as long as they would like to before each meeting, and follow up on how the parents are doing." Her group consistently has over 26 attendees.

Strength of support groups

The survey results show: support group participation is strong 59.%, support group participation is falling 33.3%, and there are other options such as the internet 16.7%.

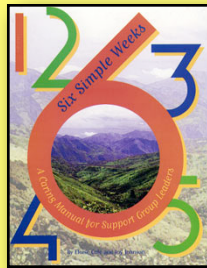
Amy who has a pregnancy loss blog writes, "All in all things are going alright here. I will be attending my support group tonight which will be very good for me. I haven't been in over three months. As sick as it is to say, I am looking forward to going. It doesn't often make me feel much better but it does make me feel less alone. Those real life meetings really help!"

Support Group Guides

www.aplacetoremember.com

Six Simple Weeks: A Caring Manual for Support Group Leaders

Ever wanted to start a good support group and didn't quite know how? Authors Eloise Cole and Joy Johnson (of the Centering Corporation) have written a great guide to get you started. Six Simple Weeks defines leadership and gives six simple weekly sessions (with readings and outlines) as a model. The goal: to make starting and leading a grief support group both enriching and fun for leaders and participants. (8.5"x11", 35 pages)



Item #SS-0302. \$8.95

The Understanding Your Grief Support Group Guide Starting and Leading a Bereavement Support Group, Alan Wolfelt, PhD

For bereavement caregivers who want to start and run an effective grief support group for adults, this new Support

Group Guide discusses the role of support groups for mourners and describes the steps involved (such as deciding on group format, publicizing the group and writing meeting plans) in getting a group started. Responding to problems in the group is also addressed, as is a model for evaluating your group's progress.

The Guide includes potential meeting plans that interface with **Understanding Your Grief** and the companion journal as texts for group participants. In addition, information is included on ceremonies you can use to support people in grief on special occasions and holidays. This Support Group guide is a must for all bereavement group leaders.

Item #UY-0543. \$19.95

Remembering With Love Sherokee Ilse & L. Levang

Often used as conversation starters in support groups.

An affirming gift for anyone grieving the loss of a loved one – offers compassion, comfort, support and guidance during the lonely and painful times of one's grief.

Remembering reflects the grieving process itself. During the trying early days after a loss, this book offers immediate words of encouragement for daily reading. As the weeks and months progress, issues change, and the book allows you to select the message that best speaks to you on a particular day.

Over three hundred entries, with quotes from people who have coped with their own losses are often used as conversation starters in support groups.

\$11.95 from www.wintergreenpress.com.



The following books on support groups are available from www.amazon.com :

- The Support Group Manual: A Session-By-Session Guide** (Paperback) by Harriet Sarnoff Schiff
- Death and Grief: Healing Through Group Support** (Small Group) (Paperback) by Harold Ivan Smith
- Grief Support Group Curriculum : Facilitator's Handbook** (Paperback) by Linda Lehmann
- Effective Support Groups** (Paperback) by James E. Miller
- How to Lead Small Groups** (Paperback) by Neal McBride





Letter

Dear Sherokee,

I have been meaning to write you to tell you what a great newsletter you have created! It is just packed with so much great information! (I wish there was as much information for our Japanese families in Japanese.)

Can you give me more details on the info from Dr. Jason Collins about preventing cord deaths? It would be interesting to know more about the role that cords may play in late stillbirths. Revisiting how kick count might play a role in prevention and with all the advances in medical care, stillbirth prevention has become a hot topic! Many organizations are starting to focus on this topic. I believe that sharing this kind of important information through your newsletter will spur progress in preventative care and save some babies' lives!

Thanks for all the work that you do and thanks for your vision!

Sincerely,
Stephanie Fukui, Executive Director
SIDS Family Association Japan

Dear Stephanie,

Thank you for your compliments about our newsletter. I am happy that you find it useful. Maybe it can be used to help inspire more participation in your community/country and those of others. That is one of my hopes. The more we help each other and use the available resources, the easier it will be to get more things done.

As for your question about cord accidents, (nice low blood pressure, placental issues), and kick counting. I believe that could take up almost an entire newsletter sharing the body of knowledge that now exists...and maybe that is exactly what I will do soon. If there are studies and empirical data (and there is) that shows that something *may* save babies lives, even a few lives, I think we all have a responsibility to look deeper into it, especially if the actions that parents and doctors could take aren't harmful to mom or baby. Such is the case with the work of the following researchers and doctors. I do hope that readers will share this with their doctors/midwives in hopes they will research them and come to their own conclusions.

I will quickly summarize some of the studies and articles. Then I will also list them all on my website under Stillbirth Research. In a future newsletter, I'll cover this more extensively. Maybe some of the researchers will write a piece. In addition, I will present the present work that is being done by the National Stillbirth Society www.nss.org, First Candle www.firstcandle.org, and others on kick counting. Given that about 80% of moms who had stillborns suspected something was wrong... actively involving mothers in observing their baby's movements and using their intuition in the baby's well-being makes sense.

For more information (very detailed, graphic, and clinical...with pictures of the cords and babies who have died) visit Ob/Gyn Dr. Jason Collins' site – www.preginst.com. As one mom recently stated, "Dr. Collins has worked for 25+ years to save babies lives. His pioneering work has opened doors, inspired others, and is setting the stage for positive movement in stillbirth prevention."

1. *Overburdened and Undernourished*, Angelika Bord, MD, Yatel, Valsky, Dept. of OB/GYN, Hadassah-hebrew Univ. Med center, Jerusalem, Israel, www.AJOG.org (full article available), Sept. 2007.

Cord obstruction, signs of severe, IUGR (growth restriction), and nuchal cord (around the neck 4 times) resulting in heart decelerations, baby delivered early but alive.

2. *Placental histologic criteria for umbilical blood flow restriction in unexplained stillbirth*, Mana Parast, MD, PhD, Crum, Boyd, Hbrigham and Women's Hospital and Harvard Medical School, Human Pathology, Vol. 39, Issue 6, pages 948-953, 2008.

Summary: "Fatal hypoxic injury due to restriction of umbilical blood flow ('cord accident') may be causal in a subset of unexplained late pregnancy stillbirths. Minimal histologic criteria' suggestive of cord accident were defined as a vascular ectasia and thrombosis within the umbilical cord, chorionic plate, and/or stem villi... Thus, we find nonacute cord compression implicated in over half of "unexplained" third-trimester stillbirth."

3. *Ultrasound Diagnosis and Management of Umbilical Cord Abnormalities*, Junichi Hasegawa, Ryu Matsuoka, Kiyotake Ichizuka, Akihiko Sekizawa, Takashi Okai Department of Obstetrics and Gynecology, Showa University School of Medicine, Tokyo, Japan. Taiwan J Obstetrical Gynecology, March 2009, Vol 48, No 1

Summary: "The incidence of placenta and umbilical cord abnormalities is high in abnormal course of the delivery. Although the detection rate of umbilical cord abnormalities is steadily increasing with the improvement of ultrasound technology, and the fact that ultrasound scanning can distinguish umbilical cord conditions, this information has not exerted much impact on the management of labor to date. Prenatal detection of umbilical cord abnormalities can reduce the number of emergency cesarean sections and intrauterine fetal deaths. In this review, the authors describe the ultrasound diagnosis and management of major umbilical cord abnormalities, including abnormalities of cord insertion site (velamentous and marginal cord insertion), hypercoiled cord and nuchal cord, considering the current knowledge on physiologic and pathologic aspects of each umbilical cord abnormality."

4. *Placental position and late stillbirth: a case-control study*, Jane Warland, McCutcheon, and Baghurst, Journal of Clinical Nursing, 18, 1602-1606, 2009.

Results: "Women who had a posterior located placenta were statistically more likely to suffer a stillbirth than women who had a placenta in any other position. Posterior located placenta may be a contributory risk factor for stillbirth. Further research warranted. Implications for Practice: Nurses and midwives should be aware of this potential risk factor to monitor foetal well-being closely."

5. *Does low blood pressure increase the risk of stillbirth?* Erick Hodgson, MD and E. Norwitz, MD, PhD., Chief Resident, Yale University School of Medicine, Contemporary Ob/Gyn, October 2006.

Key point: "Despite conventional wisdom, low blood pressure (hypotension defined as a maximum diastolic blood pressure of less than 65 mm Hg) in the third trimester may not be reassuring observation. Indeed, recent studies suggest that it may be a risk factor for stillbirth. However, these data should be regarded as preliminary..."

6. *Maternal Blood Pressure in Pregnancy and Stillbirth: A Case-Control Study of Third Trimester Stillbirth*, Jane Warland, McCutcheon, and Baghurst, American Journal of Perinatology, 25(5) 311-317, April 2008
Conclusion: "This study's findings, along with the work of Steer et al, lends some credence to the findings of the earlier German studies, that maternal hypotension in pregnancy increases the risk of stillbirth, particularly borderline hypotension. Furthermore, it appears that results from our research support active management of hypertensive disease in pregnancy and that such management is reducing the risk of stillbirth in this group."

Do you like this newsletter? Would you like to see your group, organization, product or service highlighted? Place an Ad.

Reasonable prices, great exposure!

Contact info@babiesremembered.org today.

What's Happening?

I have been fortunate to travel quite a bit lately, making 'hospital calls' and 'support group appearances', as I kindly refer to them. The people I have met have truly inspired me. Therefore, I will use this column to share some of the things I am learning from others in my travels. This time let's focus on **Peer (one-on-one) Support**.

It appears the time has come to promote more parent-to-parent support opportunities for newly bereaved. When I ask staff if they are open to asking newly bereaved parents if they would like to talk, or visit in person, with another mom and/or dad, there is an openness that I have not personally seen before. This is exciting! Nurses and other professionals hold the key to what information is given and what referrals are made at the hospital. If there are resources available such as support groups or peer support parents who want to connect up, it makes sense to share that with the families. Since at least one study (see pg 2) shows that 71% of newly bereaved parents wish they had received an immediate referral, we have some data to back up the need.

Now we need more hospitals to come on board and more parents to receive some training and hook up with national/regional organizations or create their own local programs. In my visits, one question that keeps coming up is, "What about the HIPPA laws; aren't they a road block?" Some of us have studied them, done research, and talked with plenty of hospitals who make such referrals. The conclusion we have come to is this—*as long as the patient is asked if they would like to be contacted or visited by a Peer Support Parent and if they agree, there is no problem*. I have a sample form that could be signed to ensure there is permission being given if staff need written proof. Another question I hear is, "Does the hospital assume responsibility for the interactions of these Peer Support Parents?" The answer is—no, just as a 'referring organization' does not assume responsibility for a Cancer Support Group or an Al Anon group. Simply making a community referral does not infer control or responsibility on the hospital's part.

To this end, a number of us are attempting a collaborative effort to promote this idea – to help train parents, to share forms and training manuals, and maybe even to share lists of volunteer parents (with their permission, of course.) If you wish to join us, wish to connect up with an existing group, want to start your own program, wish to become a Peer Support Parent, or if you are with a hospital or other non-profit group (like a church) and wish to have help starting a program in your facility or community, contact me. I have been seriously thinking of writing a manual for starting such a program, which connects people to existing programs for materials, training, etc. (not being one to wish to re-invent wheels.) However, if you know of such a manual (not just for peer training), but one that gives step-by-step advice on creating such a program, let me know soon. That will save steps and time.

Parent to Parent Program Updates - I learned that Pat B. and staff at Tampa General are working with bereaved mom and parent advocate, Lori M. to start a Peer One-on-one Support Program, www.healingfromthestart. Tracey H. and Heather B. have a very active Peer Support Program, www.Heartstringsupport.org, in the NC area, though they receive calls from around the nation. Michie S., www.Neofight.org, Indianapolis, IN has also been running a peer support program for many years, as has Jeff H. of www.SimonProject.org. Candy M. www.missinggrace.org has

an in-hospital program where trained Peer Supports Parents help during the decision-making time (awesome). First Candle, Miss Foundation and SHARE also have peer programs.

Where I'll Be - Do you want to meet up?

I have people asking where am I going next and others wondering if I could stop in to visit their hospital. Here is what I know so far.

Late June, Beaumont, TX,

Early August, New Zealand

September, Mpls, MN

October – upstate NY (Albany area), Bangor, ME, Vermont,

Orlando and Tampa, FL,

November/December – Arizona

Jan or Feb. Tampa, FL

If you want me to visit your support group, consult with your hospital or just stop in, or schedule a training event, contact me.

The schedule is filling up. sherokeeilse@yahoo.com

Training Opportunities for Care Providers, Support Groups, Parents, or Conferences

Sherokey Ilse is available to speak on many pregnancy, infant, child loss topics as well as general bereavement. View her bio and frequently requested topics on the home page of her website- www.babiesremembered.org

Next issue: The Hospital Experience

Memorialization and resources

Picture taking

Deadline for submissions and ads Aug. 15th

Future issues:

October - Pregnancy & Infant Loss Awareness Month

Miscarriage care and resources

Miscarriage disposition – rights and laws

Slowing down the rush to the hospital

Taking babies home to die or after death to cuddle

Funerals and memorial services

Updates on research – bereavement care, causes, etc.

And so much more...

Submit your suggestions, place an ad, share a poem, etc. to sherokeeilse@yahoo.com

The following links explain how to start and run a support group:

<http://www.familyvillage.wisc.edu/General/Selfhelp.html>

<http://www.supportworks.org/shgbuild.htm>

<http://www.mentalhelp.net/selfhelp/selfhelp.php?id=866>

<http://www.selfhelpconnection.ca/startingagroup.htm>

<http://www.addcoach4u.com/support/howtostartasupportgro.html>

<http://www.grieflossrecovery.com/grief-articles/penepent02.html>

Featured Product

Support Group Cards

<http://www.griefwatch.com/pl/plinfo/supportcards.htm>

Support Cards are a new item for Grief Watch. Created for support groups, the cards are equally useful to counselors and bereaved individuals.

Each card has a gentle note that asks the user to reflect and share what they are feeling about a particular loss. \$5/deck plus shipping



Support Card Examples

How do I think my loved one would want me to grieve for him/her?

How did I view the world before my loss and how do I view it now?

What is the hardest part of my grief?

What are the most helpful words that people have spoken to me since my loss?

What will I want to tell others about the person who died? What am I learning about myself as I grieve?

How does my grief affect my daily life and activities?

What do I do now to show my love for my loved one?

Tips for Offering Support

Support Groups – Have you ever had a participant take up too much time or go off on a tangent that you deemed inappropriate or not helpful for the rest of the group? How do you handle that? One suggestion is to always be sure you have a co-leader (even if you designate one before the group starts that evening) and preplan a strategy. Agree to stop the group, for a coffee/refreshment or bathroom break, if such a thing happens. Then have one of you take the participant to a quiet place and say something like, “I can see that you have a need to talk about _____,” or “I feel you might prefer one-on-one attention right now, so let’s talk while the group continues.” This allows the rest of the group to go one and this person to be talked with privately.

Peer Support – Silence is common when interacting with bereaved people (either in person or on the phone) who are easily overwhelmed. As a supporter, you may find silence difficult and have a tendency (like most of us) to fill it – with advice, more questions, or your story. There are many reasons for silence or long pauses. Mom or dad may be processing what has been said, remembering things brought up by a comment, crying, escaping, thinking about what to say next...maybe even preparing to ask a hard question, or ??? Waiting quietly is a good idea. So the question is, how do YOU handle the silence? If you cannot stand long silences, you may

need to do something to keep your mind busy while you wait patiently. If you need to do something while waiting here are some suggestions: write down a few notes on what you know so far, consider the next issue you want to bring up, pray for the family or send positive thoughts, count to 100 by 3’s or 7’s – yes, I mean it, as silly as it sounds. You could also say part way into the silence, “I am still here and will wait with you till you are ready.”

Friend and Peer Support Parent, Lori Martini sent me an interesting paper entitled, ‘The Power or Silence’ by Bruce Himelstein, Nancy Jackson, and Linda Pegam from the Journal of Clinical Oncology, Vol 19, October 2001. The authors write of a mom who is beginning to deal with the fact that her 7 year old is about to die. “We presented options for her care to Terry and shortly thereafter the dialogue naturally came to a stop. Terry very quietly cried and then joined us in silence. During the next seemingly eternal 10 minutes, we each became aware of every stain on the rug, the expressions and held-back tears on the faces of everyone in the room, the color of everyone’s shoes, the sound of the ventilation system, and the movement of breath in the air. The silence was heavy. Terry ended it by asking, ‘What would that be like?’ Our silent presence allowed her the space and time to question, to struggle, to analyze the situation within herself...”

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