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Helping Hands

Winter 2010

Willow's Waterfall: Ritualizing grief and loss

By **Susan J. Gulbe Walsh**
HAND of Santa Cruz

How does one manage the impossible task of simultaneously preparing for the birth and the death of one's own child, as well as finding a way to move through the months and years that follow?

Last December, my husband and I had the very unfortunate opportunity of starting this seemingly unbearable journey with our daughter, Willow Jane Gulbe Walsh. Following results from a CVS procedure that indicated Willow had Trisomy 13, we were forced to engage in a 4-week spiritual, moral, and ethical decision-making process that I also experienced as an emotional and psychological crisis.

Following endless appointments with specialists (including several ultrasounds to identify more about Willow herself as opposed to trusting the general medical body of knowledge about Trisomy 13), who were all convinced that Willow's diagnosis was not "compatible with life," we made the painstaking and heart-wrenching decision to induce labor on December 21, 2009 when I was 18 ½ weeks pregnant. (As an aside, I am currently writing this 10 months later while also 18 ½ weeks pregnant with what we know so far to be a healthy baby boy; yes, miracles do happen!!)

Finding a way to ritualize our experience was the main coping mechanism toward managing this

dilemma and crisis of Willow's birth and death. While I do not currently follow a particular organized religion, education and life have taught me that the more one can pay attention, make sacred, and ritualize suffering, the more one will be able to transform this type of impossible grief into some other kind of meaningful experience.

That being said, it is worth mentioning that my husband and I independently knew that Willow's name was "Willow" (a name we had never discussed prior) and told each other about this in a conversation prior to her birth and death. A few weeks later, we learned from our OB of the Temple of the Water Babies in Japan where offerings and blessings are made through the guardian figure, mizuko jizo, for children who did not have the opportunity to be of this earth. Further, we later recognized that the Willow species thrive in water and, even more amazingly, after finding out all of this information, Willow was born completely encased, silently and (I hope) peacefully, floating in her water sack.

In terms of ritualizing our pain, the day prior to going to the hospital, women friends from a previous birthing class held a mommy circle where I could tell my story; they offered thoughts, prayers, and blessings, as well as beautiful music toward holding our family in our darkest hours. They also provided a meal train for weeks following our trauma.

Willow *continued on page 3*

HAND of the Peninsula

Ways to support HAND parents

Among the many ways one may honor the memory of their children is to give back to the organization and ensure that HAND of the Peninsula will continue to provide the caring support and other vital services for which it has become well known over nearly three decades in existence.

As a 501c3 non profit, HAND of the Peninsula is governed by a Board of Directors which welcomes new members who bring fresh ideas, talent and energy to our common endeavor. The Board meetings are held quarterly in the evening on the fourth Wednesday of the month. HAND of the Peninsula is run predominantly by parents who have experienced a loss and financed entirely with donations from parents, family and friends. Without their support, HAND would cease to exist. Consider getting involved in any of the following ways:

- * **Schedule and/or facilitate inservice trainings where a sharing parent tells their personal story to healthcare providers interested in learning how to be more sensitive and helpful to parents experiencing a loss**
- * **Library organization and management**
- * **Write and edit the quarterly newsletter, *Helping Hands*, get it to the printer and post office**
- * **Distribute brochures to area hospitals which in turn give these to parents experiencing a loss**
- * **Bookkeeping and accounting**
- * **Fundraising (donations are our sole support)**
- * **Helping with special events like the annual Service of Remembrance, Volunteer Appreciation Picnic, updating the recommended book list**
- * **Anniversary and Special Dates remembrance**
- * **Schedule meeting facilitators**
- * **Attend training and become a meeting facilitator or phone support volunteer**

If you have a talent you wish to share or would like to learn more about ways to get involved and support parents please email: volunteers@HANDsupport.org or call (650) 367-6993.

Helping After Neonatal Death

Chapters:

HAND of the Peninsula

HAND of Santa Cruz County

HAND of Antioch

HAND of San Francisco

P.O. Box 3693

Redwood City, CA 94064

(650) 579-0350 crisis line

(650) 367-6993 office

<http://www.HANDsupport.org>

Helping After Neonatal Death

Santa Clara, Alameda, Contra Costa and Central Valley counties

P.O. Box 341

Los Gatos, CA 95031-0341

(888) 908-HAND (4263)

<http://www.handonline.org>

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Helping Hands

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Submission deadline for next issue:

FEB.1, 2011

Willow *continued from page 1*

The next morning, my husband and I created an altar at the hospital with meaningful items, such as the fresh roses from the cake the group had provided the day prior. One of my husband's sisters brought an angel figure for the altar, as well as a tiny angel necklace which I wore during the delivery, 10 psychologically, emotionally, and physically painful hours after induction.

I held Willow most of the night after her birth and death, while singing to her my own words about her to the tune of "Amazing Grace." In addition to making her tiny foot and handprints, we also had pictures of her and the altar taken. Willow was cremated and picked up on Christmas Eve. Her ashes remain on an altar at home with pictures, a stone mizuko jizo, and other items of significance, like her hand and foot prints, ultrasound pictures, cards from friends and family, etc. I started a journal at the hospital when I was in labor with Willow beginning to write letters to her about our story and how we came to be there that day. I wrote her daily for weeks thereafter and have since written her every Monday (the same day of the week she was birthed and passed). I often still light candles to her and sing.

In addition to creating and sending out a memorial card, posting a memorial on the website, "A Heartbreaking Choice," as well as attending supportive HAND meetings, my husband and I searched our hearts for a way to further manage our pain; we eventually decided to build a waterfall in Willow's honor on our property. We invited friends and family to participate in "Willow's Waterfall Work Weekend" toward completing the project. We chose special stones that remind us of her and often add ones that we find that are special to us.

On her due date, May 21, 2010, my husband and I each took a small bit of Willow's ashes and released them into the waterfall with a blessing. Some small part of me was able to let go after that date; amazingly I got pregnant the following cycle. While the waterfall is complete, the surrounding area has become a huge project as we are creating a sacred garden space all around the waterfall. The project has become much larger in time and money than we had ever anticipated, and will clearly take years of energy, but it is a wonderful way to channel our grief. We have planted a Willow tree and have one more tree, as well as a Willow bush, to plant in her honor.

My grief continues to ebb and flow and transform. Some days are good, others are horrible. I still have an experience of intense lonely

ness, in part because there is not a lot of literature or support for this particular kind of loss, one in which many people lump into the category and subsequently judge as an "abortion," as opposed to a compassionate or merciful sacrifice. (I certainly have my own demons around the thought that I knowingly participated in my own baby's death.)

I am currently working on finding a way to manage the upcoming one-year anniversary of Willow's birth and death, December 21, 2010 at 6:30 p.m. One thing I have been reflecting on often is that my 2-year-old daughter was born on the Summer Solstice, Willow was born and died (or died and was born) on the Winter Solstice, and I am currently pregnant with a son who is due on the Spring Equinox. There is some magical meaning in all of this that I am trying to pay attention to. One thought that keeps me somewhat sane in the most intense moments of grief is that Willow's sacrifice on the darkest day of the year has allowed her brother's life which may come on or near the time of year we begin to move into more light.

Some other ideas for managing or ritualizing significant dates and times that can be particularly painful, such as holidays, birthdays, anniversaries of loss, due dates, etc. include: Making art like a collage about your feelings or with pictures of your baby or even drawings of who you imagined he/she to be; building an altar of all the meaningful items from your pregnancy and loss; writing poems, stories, or letters about/to your baby; singing, creating, or listening to soothing music; and participating in physical activity like hiking in nature, swimming, or dancing, which all can be very healing.

I have also learned that sometimes it is ok to simply "check out" when the feelings of shame, anger, and sadness become too overwhelming. For me, some days require curling up with Harry Potter or watching a comedy to just get through. Everyone's grief process has its own way and own time, so self-compassion is an absolutely key element in working through these seemingly unbearable experiences.

I will close this story with a note to Willow in a fashion similar to when I open and close all of her letters in my journal:

Dear sweet Willow Jane: You touched my heart through and through. You have taught me more about life and death in 10 months than in my past 43 years. While I feel like much of my innocence has been ripped from my soul, I have new wisdom that I can use in relationship to you, myself, and others. I will never forget you and I will always honor you for your tremendous sacrifice. I hope you are peaceful my little spirit. I love you, Mommy

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 the Peninsula

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

Contact: (650) 367-6993

Time: 7:30-9:30 P.M.

Dates: Dec. 1 and 15
Jan. 5 and 19, 2011
Feb. 2 and 16
March 2 and 16

Location: Follow signs to Palm Room at Mills Health and Wellness Center, 100 S. San Mateo Dr., San Mateo

HAND of Santa Cruz Co.

Support meetings are held on the third Wednesday of the month. Contact: Kristie Shulman (831) 438-4513

Time: 7:30-9:30 P.M.

Dates: Dec. 15
Jan. 19, 2011
Feb. 16
March 16

Location: Congregational Church of Soquel

HAND of Antioch

Support meetings are held on the first Thursday of the month. Contact Elham Raoufian, (925) 437-3406 for location.

Time: 7:30-9:30 P.M.

Dates: Dec. 2
Jan. 6, 2011
Feb. 3
March 3

HAND of San Francisco

Support meetings are held on the first and third Wednesday of the month. Contact: Chris Lehr, LCSW, (415) 282-7330.

Time: 6:30-8:30 P.M.

Dates: Dec. 1 and 15
Jan. 5 and 19, 2011
Feb. 2 and 16
March 2 and 16

Location: Davies Campus of CPMC, Castro at Duboce, Support Services Conference Room, Level B

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 the Peninsula

holds subsequent pregnancy support meetings on the second Wednesday of the month at Mills Health and Wellness Center, 100 S. San Mateo Dr., in San Mateo. Contact: (650) 367-6993.

Time: 7:30-9:30 P.M.

Dates: Dec. 8
Jan. 12, 2011
Feb. 9
March 9

HAND of Santa Cruz Co.

Subsequent pregnancy meet-

ings are held on the first Wednesday of each month. Contact: Kristie Shulman (831) 438-4513

Time: 7:30-9:30 P.M.

Dates: Dec. 1
Jan 5, 2011
Feb. 2
March 2

Location: Congregational Church of Soquel

Births

Max Nagata Chernomaz — April 27, 2010, to Kirill and Ryoko Chernomaz

Isaac Shiloh Nelson — August 31, 2010, to Cassandra and Jake Nelson and big sister Abigail

Celso Valentin Salinas-Holz — September 2, 2010, to Jen and Gabriela Salinas-Holz and big brother Desi

Sophia Isabel Olea — Oct. 26, 2010, to Cristina and Ricardo Olea

Lucas Ryan Crespo — Oct. 29, 2010, to Jay and Penny Crespo and big sisters Sydney and Ella

Donations

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

Panten Naeimi and Jafar Tay, in memory of Donya Naeimi Tay on her 1st birthday

Kathleen Addison, MA, MFCC in memory of PJ and baby Mac
Emily Mockett and Phil Hutcherson, in memory of Julia Mockett Hutcherson, on the 8th anniversary of her lifetime

Elmira Cruz, in memory of Joseph Castro

Deborah Robinson, in memory of Sean Patrick Robinson

Theresa and Jason Meador, in memory of Kyle Meador

Shannon Casey-Cannon and Steve Cannon

Mary and William Schorr, in memory of Daniel Patrick Schorr

Thomas Corso,

Marianne and Peter Pignati, in memory of Anthony Orlando Madrid

Catherine and Gary Simms, in memory of Montgomery Anthony Shew

HAND of the Peninsula
Volunteer Training
Two half-day, free workshops
Saturday, January 22 and 29, 2011

For HAND parents interested in giving back by facilitating meetings or offering phone support to parents with a recent loss, their relatives and friends. You are welcome to participate whether you feel ready to jump in and help right away or down the road.

***For more information call (650) 367-6993
or email volunteers@HANDsupport.org***

"I volunteer because HAND was a bright light for me at a very dark period in my life. Now that I am in a much better place I would like to 'be there' for someone the way someone was there for me. Going through the training cemented the fact for me that although we all have different experiences, our feelings can be very similar. Grief is not a static process but can be messy, a two-steps-forward one-step-back kind of process."

**— Lisa Sass
HAND of the Peninsula**

"I came to this from my prior work as a hospital social worker. I have found it very inspiring to have met so many loving parents, and heard about so many loved and missing babies. I have met many bereaved parents who eventually find happiness with healthy babies after their children's deaths. The training was really excellent, with a chance to hear the experiences of other facilitators and bereaved parents. I learned a lot of useful tips and left with great hand-outs and connections with other HAND parents."

**— Chris Lehr, facilitator,
HAND of San Francisco**

HAND of the Peninsula

Board welcomes two new members

Cassandra Musgrave-Nelson grew up in Santa Cruz and moved to San Mateo 15 years ago. She and her husband, Jake Nelson, came to HAND of the Peninsula in 2008, after the loss of their second child, daughter, Margaux, who was stillborn at 41 weeks due to an umbilical cord accident.

After attending her first HAND meeting, it became evident to her that she was going to get involved and give back when the time was right. She is happy to help those who have been working so hard behind the scenes, and honored to help bring some peace to other families in need. She loves spending time at home with her family. Her 5-year-old daughter and 2-month-old son keep her constantly humbled and amazed.

Jennifer Gilbert came to HAND of the Peninsula in January, 2007, following the stillbirth of her daughter, Grace, at full-term. The cause was a cord accident. Jennifer and her husband, Rob Fagen, have three children, Eloise, 9, Lucy, 7, and Isaac, 2 1/2. Until recently, she ran the Finance and Supply Chain Management groups at Maxim Integrated Products. By joining the Board, she hopes to support the organization in its mission of helping grieving parents.