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Still Unanswered, Always Remembered: The Powerful Legacy of Stillbirth

By Ann Douglas

“Childbearing losses may affect women and their families for a lifetime. The effects of childbearing losses may occur well after the childbearing years have ended.”

- Wisconsin Association for Perinatal Care

Stillbirth is a life-altering event that forever changes the landscape of parenthood. It affects who you are as a parent and how you raise both your living children and any children you may subsequently give birth to.

It affects your stillborn baby’s siblings and grandparents in all kinds of profound and powerful ways.

And the shockwaves continue to be felt in other branches of your family, rippling out to all those countless aunts, uncles, great-grandparents, cousins, and other family members who were eagerly anticipating the birth of your baby, and who are both shocked and devastated by your baby’s stillbirth.

Yes, stillbirth is a *family loss* because it represents the death of a tiny bud off the branch of your family—a bud that carried with it the hope for your family’s next generation. That’s why the stillbirth of a baby seems particularly heartbreaking to grandparents and great-grandparents. It cruelly disrupts the natural order of things.

That’s why so many parents who have experienced the death of a baby through stillbirth spend the early days and weeks after their baby’s stillbirth trying to make the senseless make sense. They may embark on a seemingly tireless quest for explanations. They’re seeking both medical answers and an answer to the largely unanswerable question: “why us?” They may also feel themselves playing “the blame game”—the most emotionally gut-wrenching game ever invented for parents because the prize for “winning” this particular game is a life-time supply of guilt.

Mothers and fathers tend to follow different paths when it comes to grieving, something that can lead to conflicts in the couple’s relationship if they get into arguments about who is or isn’t grieving “properly.” They may also experience conflicts about a lack of connection with one another and reduced sexual intimacy (particularly if one or both are struggling with depression). It’s important for bereaved parents to talk through these issues as they arise in order to

prevent these common sources of conflict from becoming long-standing relationship issues.

The way parents grieve can affect their ability to care for and relate to any living children, including any children who are subsequently conceived and born following the loss. (This only makes sense. Grief is an exhausting emotion.) If the mother is having difficulty coping with her grief feelings, she should be encouraged to talk to her doctor, a counselor, or a trusted friend about how she is feeling. It's important to seek support when you're struggling.

Many parents who have experienced a stillbirth choose to attempt another pregnancy. Couples embarking on a subsequent pregnancy should make a point of choosing a healthcare provider who will provide them with the information and support that they will need to weather the emotional highs and lows of what may feel like the longest nine-and-a-half months of their lives. Some of the challenges that couples can expect to grapple with during a subsequent pregnancy include coping with their fears about the well-being of the baby and finding individual ways of feeling "safe"; trying to make sense of the fact that pregnancy is supposed to end in "birth" but their previous pregnancy ended in "death"; and dealing with conflicting feelings of hope and fear, optimism and pessimism. They are likely to talk about "surviving" pregnancy rather than enjoying it.

While stillbirth changes your life forever, it doesn't have to mean that you will never be happy again (although you may feel that way initially). You may find that you are able to find a renewed sense of purpose in life once you survive the initial shock of your baby's stillbirth—an increased determination to make every moment count now that you have had an all-too-poignant reminder of just how precious life really is, and why it should never be taken for granted.

Sidebar: Some key facts and statistics about stillbirth and parental grief:

- 20% of mothers who have experienced stillbirth experience a prolonged episode of depression and one in five mothers suffers from post-traumatic stress disorder.
- Recently, there has been growing evidence to show that stillbirth (like SIDS) can result in post-traumatic shock disorder. A study in the Netherlands found that 25% of women displayed symptoms of post-traumatic stress disorder one month after the stillbirth and 7% displayed such symptoms four months after the stillbirth.
- Some of what a mother experiences when her baby is stillborn is so traumatic that she may not feel comfortable discussing the details of her baby's stillbirth with anyone other than another stillbirth parent or a professional with expertise in perinatal bereavement.
- Mothers who experience stillbirth are at risk of developing postpartum major depression. The risk of depression is highest within the first six months after

delivery. The mothers who are at greatest risk of becoming depressed are those who fail to show any signs of grief during the first two weeks after the stillbirth or whose grief does not show any signs of diminishing six to nine months after the stillbirth.

- Thoughts of suicide are not unusual in the aftermath of stillbirth. 30% of mothers report having had such feelings.
- Grief in fathers tends to peak around 30 months after the death of a baby, whether that baby is stillborn or whether that baby dies shortly after birth (2002 study, University of Queensland, Australia)
- A study conducted by Swedish researchers (2001) concluded that fathers' "general trust in life and the natural order was suddenly and severely tested by the death of their child, which they perceived as a terrible waste of life." Being able to protect their partner and grieve in their own way was important to the fathers interviewed by this group of researchers.
- Here's what the Canadian Paediatric Society has to say about the grieving couple: "Although parents struggle over the death of the same child, each partner actually has sustained a different loss and has a unique mourning experience. Normal synchronicity of grief and mourning between two individuals means that bereaved parents are seldom at the same phase of grief at the same time because of their roles in the family, normal fluctuations in grief and differences in how they respond to the different phases of grief. Data suggest that the incongruence between spouses dramatically increases from two to four years after the death of a child. After the fifth year, it declines slightly."
- First-time parents who experience a stillbirth may not have their support networks in place. They may be new to a community. It is particularly important for friends, family members, and health care professionals working with these parents to help them to tap into both formal and informal supports in the community.
- Sexual intimacy will provide comfort to some couples, allow others to express affection, and act as a painful reminder of the loss to others (1995 study, Child Bereavement Trust, UK).
- The loss of one or more multiples can take a particularly long time for a parent to process. One study found that it took parents three to five years to be able to incorporate their loss without significant sadness or depression. Part of the challenge is trying to find the language to label surviving children (e.g., two surviving triplets are not twins).

Sidebar:

What Doulas Can Do To Support Parents Through Stillbirth, Intrapartum Loss, and Infant Death Immediately Following Birth

- Be physically and emotionally present with parents in the aftermath of their loss. If there is a possible indicator ahead of time that the parents may receive bad news (e.g., an ultrasound is scheduled to try to assess the baby's

well-being after mom has reported a lack of fetal movement), see if the parents would welcome support at that ultrasound appointment, just in case the news is not what they are hoping for.

- Help parents to make memories by relating to their baby as a person and helping them to gather information, collect special items that can hold/look back on later, and -- in the case of a stillbirth or infant death -- support them as they spend time with their baby after the stillbirth/death. You may want to routinely carry a spare disposable camera in your labor kit so that you will always have an extra camera available that you can give to parents.
- Be prepared to support parents as they deal with all kinds of incredibly difficult decisions: the removal of life support options, funeral options, autopsy decisions (in 44% of cases, an autopsy will yield “clinically useful information”).
- Realize that you will need some support when you are not with the parents. The death of a child is extremely upsetting to everyone, especially caregivers who care deeply, as doulas do.
- If the parents are frightened/scared about what labor may be like or simply afraid of “going crazy” because of their grief, talk to them about these fears. (Use perinatal bereavement organizations or other people you know as resources if you don’t have any firsthand experience with perinatal loss.) Sometimes what the parents are afraid of isn’t a “realistic” fear, but it’s real to them.
- Try to feel out to what degree the parents would like the baby swaddled when you’re offering this type of support. Some babies want to see their whole baby, “no matter what.” So parents may wish to have a baby with a severe, highly visible birth defect swaddled in a particular way. Help them to understand their choices ahead of time so that they can make the best choices for themselves. And always handle their baby as you would a living baby -- lovingly and with respect.

Resources

American Organizations

Centering Corporation
7230 Maple Street
Omaha, NE 68134
(402) 553-1200
www.centeringcorp.com/catalog/
Provides books and workshops about grief.

CLIMB (Center for Loss in Multiple Birth)
P.O. Box 91377
Anchorage, AK 99509
(907) 222-5321
www.climb-support.org

By and for parents who have experienced the death of one or more babies from a multiple pregnancy.

The Compassionate Friends
P.O. Box 3696
Oak Brook, IL 60522
(877) 969-0010
(630) 990-0010

www.compassionatefriends.org

Grief support for parents who have lost a child at any age.

The MISS Foundation
Mothers in Sympathy and Support
P.O. Box 5333
Peoria, AZ 85385

www.missfoundation.org

An international organization providing support to grieving families.

National SIDS Resource Center
2070 Chain Bridge Road, Suite 450
Vienna, VA 22182
(703) 821-8955

www.sidscenter.org

SIDS-related information for families and health care providers.

A Place to Remember
1885 University Avenue, Suite 110
St. Paul, MN 55104
(800) 631-0973
(651) 645-7045

www.aplacetoremember.com

Support and information for parents who have experienced perinatal loss.

SHARE Pregnancy and Infant Loss Support
St. Joseph Health Center
300 First Capitol Drive
St. Charles, MO 63301
(800) 821-6819
636-947-6164

www.nationalshareoffice.com

Grief support and information for parents experiencing perinatal loss. 130 chapters worldwide.

Wintergreen Press
3630 Eileen Street
Maple Plain, MN 55359

(952) 476-1303
www.wintergreenpress.com
Grief resources.

Canadian Organizations

Perinatal Bereavement Services Ontario
6060 Highway 7, Suite 205
Markham, Ontario, L3P 3A9
Telephone: (905) 472-1807
Toll Free: 1-888-301-PBSO (7276)
Fax: (905) 472-4054
E-Mail: pbsocares@pbsso.ca
www.pbsso.ca
Grief support for parents who have experienced a perinatal death.

Canadian Foundation for the Study of Infant Deaths
586 Eglinton Avenue East, Suite 308
Toronto, Ontario M4P 1P2
Tel: (416) 488-3260
Toll-Free: 1-800-END-SIDS
email: sidsinfo@sidscanada.org
www.sidscanada.org
Grief support for parents who have experienced an infant death.

Bereaved Families of Ontario
36 Eglinton Avenue West, Suite 602
Toronto, Ontario M4R 1A1
Tel: (416) 440-0290
Fax: (416) 440-0304
Email: See <http://www.bereavedfamilies.net/email.html>
www.bereavedfamilies.net
Grief support for parents who have experienced the death of a child.

Internet Resources

Having-a-baby.com (Ann Douglas)
Miscarriage, stillbirth, infant death, and bereavement articles and Q&As.
http://www.having-a-baby.com/article.htm#Pregnancy_Loss

2005 First Candle/Stillbirth Alliance 2005 Conference: Conference Library (articles and other resources)
<http://firstcandle.org/conf2005/>

Cacciatore, Joanne, CT, MSW. *Effects of Support Group Participation and Psychosocial Intervention on Post Traumatic Stress and Grief Responses*

in Women Experiencing Sudden Intrauterine Infant Death. Peoria, Arizona: MISS Foundation, 2005. Available for download from <http://www.missfoundation.org/research/index.html>

Guidelines for Health Care Professionals Supporting Families Experiencing A Perinatal Loss. Fetus and Newborn Committee, Canadian Paediatric Society (CPS) Paediatrics & Child Health 2001 6(71): 469-477. Reference No. FN01-02
<http://www.cps.ca/english/statements/FN/fn01-02.htm>

Väisänen, Leena. *Family Grief and Recovery Process When A Baby Dies*. Oulu, Finland: Department of Psychiatry, University of Oulu, 1999.
<http://herkules oulu.fi/isbn9514254295/isbn9514254295.pdf>

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Ann Douglas is the author of *The Mother of All Pregnancy Books* and *Trying Again: A Guide to Pregnancy After Miscarriage, Stillbirth, and Infant Loss* and the mother of four children, ages 7 through 17. Her daughter Laura was stillborn due to an umbilical cord knot in 1996. You can find additional perinatal bereavement links and resources on Ann's website at www.having-a-baby.com and in the links section of her blog at <http://anndouglas.blogspot.com>.