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## Finding Hope in Sorrow: Support for parents experiencing the unthinkable

by Chris Wolfe

As a parent, you face many challenges – but no tribulation is as daunting as the death of one of your children. This event heartlessly upsets the flow of life and can leave you feeling helpless and adrift with a hole in your heart that never completely heals. You feel alone and lost.

Though difficult to believe while amidst the throes of grief, it doesn't have to be this way.

Through the passionate work of people like Joanne Cacciatore-Garard of Peoria, founder of the MISS Foundation, and Gene Caligari, a local support group leader for The Compassionate Friends, family, friends and caregivers have a place to turn to for encouragement and information on surviving the loss of a child. The once taboo subject has now been given the space it needs to be discussed, and society is now finding the tools to help families survive and even thrive after the death of a child.

It starts with support and continues onto hope.

As a parent who has come through the crushing grief of infant loss, I can tell you there will be a time when the loss of your child will not define your life, but will be a defining moment within it. My son, Daniel, would have been 6 in October. He died of an undetected heart defect when he a 2-weeks-old infant. And while the stabbing, staggering pain has mellowed, there are still days when I cry just thinking of him. But there are also days when I smile and remember how he smelled of Baby Magic lotion.

“The death of a child transverses race, age and socioeconomic boundaries and affects families in a profound way,” explains Cacciatore-Garard, who started the MISS (Mothers In Sympathy & Support) Foundation in 1996, following the death of her daughter, Cheyenne. “Our mission is to help connect people to the resources they need as individuals and families, and to ensure families are surrounded by a circle of compassion after the death of a child.”

That circle of compassion can take any form – from church members to support groups to friends and family – anyone can be helpful. Cacciatore-Garard started MISS so other parents would not have to experience the debilitating grief alone – as she did when Cheyenne died.

“The pain was completely incapacitating,” Cacciatore-Garard remembers. “I didn't eat well, I couldn't remember where I was going or what I was supposed to do. All I could manage some days was to brush my teeth.”

### Reaching Out

When Asena Nicolosi's 3-year-old daughter drowned, she looked to MISS

for support during the dark days that followed. "The best advice I got from Joanne was this: If you can't get through the next hour, then focus on getting through the next five minutes. And if you can't get through the next five minutes, then focus on getting through the next breath," she says. This advice she now passes along to families who attend the MISS support group she leads at Saint Francis Xavier Church in Phoenix. There are still times when the grief makes her voice thick with tears, but she has chosen to move forward and work through the pain. For Nicolosi, it's been the only way to survive the "what ifs" that charge through her mind.

"It's important to have a phone list of people you can call in the middle of the night who understand what you are going through," Nicolosi says. "Depending on what stage of grief you are at, find a support group, journal and talk about your child. I found MISS one month after she died, when I couldn't imagine living one more day without her. Without MISS, I wouldn't have made it this far."

Gene Caligari, who facilitates the Mesa/East Side chapter of The Compassionate Friends, a national organization that helps bereaved families upon the death of a child, says participation in a support group provides a needed component to the healing process that society often ignores. This is especially true in the death of a child, which many people shy away from discussing.

"The emotional support and compassion, largely absent in our society today, that you will receive from such a group is critical and essential to a healthy grieving process for both individuals and family," Caligari says. "Our society is largely inept at addressing the issues of death and dying in a manner healthy and compassionate to the family."

Because society is unaccustomed to talking about the death of an adult, let alone a child, well-meaning friends and neighbors often utter inane phrases in their effort to comfort your pain. Statements such as "You can always have another one," or "It was for the best" feel like a blow to the chest of a bereaved parent.

The one that still stuns me is "So, when are you going to be over Daniel's death?" The pain is not something you ever "get over." The grief is something you work through, and most days I am able to smile and not have tears spilling down my cheeks. Other days my heart gets stuck in my throat and I can't breathe, the pain is so immense. Such is the nature of the grief process.

### **Grieving Differences**

Although a man's grief takes on a different form and look, the father of a dead child still aches as unbearably as the mother. The differences in the way men and women grieve can add to the trauma of the child's death if both parties do not communicate with each other.

While a 1999 study of bereaved parents published in *Bereavement Magazine* found only 9 percent divorced following the death of a child, 24 percent considered it. Feelings of guilt over the death of the child often precipitated divorce, the study found, particularly if the couple were unable to communicate their grief effectively to their partner.

Caligari says men are indeed treated differently by society and are programmed from birth to respond differently to grief. "Men are viewed by society as provider and protector of family, and as such are given their two-week 'programmed' grieving period, after which they're expected to get on with life," Caligari explains. "All of which is a grave misnomer that allows for potentially devastating consequences effecting both the individual and the entire family."

Reaching out to fathers, particularly Spanish-speaking dads, is one of the ways Roberto Sanchez of Phoenix is helping to heal his broken heart. His son, Dominick, was stillborn in June of 2003. Following the boy's death, Roberto assumed the traditional role of taking care of his wife, Andra, supporting her and suppressing his own grief to some extent. After becoming involved in a support group through MISS, he began healing by reaching out to other men who had lost a child.

"I feel it's my responsibility to be there for other people, like someone was there for me," Sanchez says. "I think it's Dominick's legacy that I help people who don't have anyone to listen. And it gives me a place to tell people that I'll always love him and remember him."

Men are not usually encouraged to cry, or even talk about their dead child. Many times friends won't even broach subject, for fear of making things worse. "People try to comfort you, but they don't know what to say. How could they, unless they've gone through the same thing? People move on, and expect you to do the same. But you can't, because you're still grieving," Sanchez says.

### **Comfort and Hope**

You don't have to run a support group or be a licensed grief therapist to offer comfort to bereaved parents. Sometimes all it takes is a willingness to just listen. Grieving parents want to tell you about their child – if you will only ask. Cacciatore-Garard suggests offering words of sympathy such as "I'm sorry for your loss," or "I'm here for you." Never say you know what they are going through, unless of course, you do. When Daniel died, the simple gesture of someone doing our laundry or taking our 3-year-old to the park was an immense comfort and relief.

"I encourage people to help by doing practical things, such as dropping off dinner or offering to care for the bereaved parents' other children," Cacciatore-Garard says. "It's important to offer to sit with kids or take care of household chores so Mom and Dad can go out for a night." Don't intrude, but be available if needed.

The grief process is life-long. There is no set timeline for grief's various stages. The quality of the pain changes over time, but it never completely disappears. Some days are easier to be at peace; other days you're angry for no reason, Cacciatore-Garard says. At the end of the day, it's about how well you've come through and how well you've adapted healthy coping skills.

"It's okay to ask for help when you need it," Cacciatore-Garard explains. "You will emerge transformed from this process of grief and be able to transcend it on every level. But you will hurt for a very long time, and people need to recognize that."

### Helping Children Cope with Grief

When children are affected by the death of a family member, their grief is expressed in different ways. The MISS Foundation offers the following guidelines to help children heal.

- Children are 'concrete' thinkers. Avoid expressions such as "passed on" or "went to sleep." Answer questions about death simply and honestly. Only offer what they can absorb, and don't overload them with information.
- Children are physical in their grief. Watch their bodies and support their play/behavior as their "language" of grief. Encourage art therapy as a healthy outlet for expression.
- Children can be fearful about death and the future. Give them a chance to discuss their fears and validate their feelings. Share happy memories about the person who died. Offer an alternate adult for talking and sharing since children are sometimes hesitant to express their true grief with their parents. Support groups specifically for children are also healthy outlets for expression.
- Children grieve as a part of a family. Children grieve the person and the "changed" behavior and environment of family and friends. Keep regular routines as much as possible. The golden rule of grief is not to make any major decision for the first 18 months.
- Children need to see the adults in their lives modeling a grieving process; acknowledging how one feels and talking about the loved one. Share an "open emotion" policy and allow yourself to cry, wherever and whenever you feel the need. Your openness validates their feelings.
- Children are repetitive in their grief. Respond patiently to their uncertainty and concerns. Expect their grief to revisit in cycles throughout their childhood or adolescence. A strong reminder, such as the anniversary of a death, may reawaken grief. Make yourself available to talk.

## What to Say and Do

When a child dies, well-meaning family and friends may be uncertain about what to say to grieving parents. The MISS Foundation has compiled this list of suggestions.

### DO

- Ask, "How are you REALLY doing?"
- Remember you can't take away their pain, but you can share it and help them feel less alone.
- Let your genuine concern and care show.
- Call the child by name.
- Treat the couple equally. Fathers need as much support as mothers.
- Be available...to listen, to run errands, to drive, help with the other children, or whatever else seems needed at the time.
- Say you are sorry about what happened to their child and about their pain.
- Accept their moods whatever they may be, you are not there to judge. Be

- sensitive to shifting moods.
- Allow them to talk about the child that has died as much and as often as they want.
- Talk about the special, endearing qualities of the child.
- Give special attention to the child's siblings – at the funeral and in the months to come (they too are hurt and confused and in need of attention parents may be unable to give).
- Reassure the parents they did everything they could, and the care the child received was the best possible.
- Put on your calendar the birth and death date of the child and remember the family the following year(s). That you remember the child is very supportive.
- Extend invitations to grieving parents. But understand if they decline or change their minds at the last minute. Above all continue to call and visit.
- Send a personal note or letter or make a contribution to a charity that is meaningful to the family.
- Get literature about the grief process to help you understand.

#### **DON'T**

- Be afraid to ask about the deceased child or share memories.
- Think that the age of the child determines its value and impact.
- Be afraid to touch; it's often more comforting than words.
- Avoid them because you feel helpless or uncomfortable, or don't know what to say.
- Change the subject when they mention their child.
- Push the parents through the grieving process.
- Encourage the use of drugs or alcohol.
- Ask them how they feel if you aren't willing to listen.
- Say you know how they feel (unless of course, you do).
- Tell them what they should feel or do.
- Try to find something positive in the child's death.
- Point out that at least they have their other children.
- Say they can always have another child.
- Suggest they be grateful for their other children.
- Think death puts a ban on laughter. There is much enjoyment in the memory of time spent together.

#### **Clichés to Avoid**

- Be brave, don't cry.
- It was God's will; or it was a blessing.
- Get on with your life. This isn't the end of the world.
- God needed another flower in his garden.
- At least it wasn't older.
- You must be strong for the other children.
- You're doing so well.
- You're young; you'll get over it.
- Time will heal.

## **Bereavement Support**

There are many resources for families, friends and caregivers suffering from the loss of a child. Here is a partial list of resources: many others exist and can be found by contacting one of the groups listed.

**MISS Foundation:** 623-979-1000, [info@missfoundation.org](mailto:info@missfoundation.org), [www.missfoundation.org/group/found.html#AZ](http://www.missfoundation.org/group/found.html#AZ)

**SHARE Pregnancy & Infant Loss Support, Inc.:** Maricela Rincon, 520-743-8883, [www.nationalshareoffice.com](http://www.nationalshareoffice.com)

**Compassionate Friends:** Gene Caligari, Mesa/Eastside Chapter leader, 480-659-7575, [www.compassionatefriends.org](http://www.compassionatefriends.org), [http://tcfphoenix.org/meeting\\_info.htm](http://tcfphoenix.org/meeting_info.htm)

**AGAST:** Alliance of Grandparents, a Support in Tragedy, 888-774-7437, [www.agast.org](http://www.agast.org)

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