



M.I.S.S.ing Angels ...

The M.I.S.S. Foundation

A Sanctuary for Bereaved Families

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Why Did My Child Die: Faces of Why

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Why me? Why did my child die? Those are questions that preoccupy parents who have experienced the death of a child, despite the age or cause. And while the question may seem straight forward, there are no simple answers.

When a child dies, the question of "why?" has three varying dimensions. Parents have a need to discover the **clinical** "why." What failed? What was the weakness of body that resulted in my child's death? They need to know the **rational** "why." What events lead to my child's death and were they avoidable? Finally there is the **spiritual** "why," as in, how could God let something like this happen (often precipitated by the belief that a merciful God would not let this happen, thereby challenging their own spiritual ideals).

My experience was no different from any other parent when my daughter Cheyenne died in 1994. The anger, followed by denial and then

ultimately acceptance, were stages I had to go through before I could make sense of this tragedy. I found by persuading myself to face the emotions head on I was able to come to several personal resolutions with my grief. But first I had to work through each of the questions in my mind.

The Clinical "Why"

The clinical answer to "why" may be ambiguous. There may be a succinct determination of the diagnosis of death after the autopsy or there may not be. Some people, from stillborn children to the elderly, die without determinable cause. This merely indicates that, for whatever reason, the medical examiner was unable to establish the mechanism or causal factor in the child's death. This inability to find a cause of death is called many things: in terms of stillbirth it is called SADS or sudden antenatal death syndrome, in infants it is called SIDS or sudden infant death syndrome, in toddlers or older children it is known as SUDS or sudden unexplained death syndrome, in adults

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Passages 2001: A Conference to Remember

The MISS Foundation held its first annual conference for grieving families and the professionals who serve with care on June 29-30, 2001. Passages 2001, the conference theme, was an enormous success.

More than 330 people attended the two-day conference including nearly 30 children who had experienced the death of a brother or sister, or other core family member. Seven countries were represented and individuals from 15 states, including parents and professionals. It

was a time to learn, heal, and meet new friends.

The children's retreat included a visit from Phoenix Fire Department academy recruits. Children had an opportunity to drive in a real ladder fire truck and even spray the hose. The Phoenix Police Department brought out a patrol car and the children were able to explore the police department's race car! Adventure Sam, a magician specializing in working with

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Take Note:

- New MISS Chapters are forming now! See page 23 for Chapter information.
- Peer contact information available in every issue of our newsletter. See page 13.
- Second Annual MISS Foundation Conference! May 23-25, 2002

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it can be referred to as SUND or sudden unexplained nocturnal death.

The absence of a diagnosis is very rare, except in full term stillbirth where, according to the National Institute for Health (NIH), nearly 60% of stillbirths have undeterminable causes. More often in other cases, however, medical examiners are able to find a cause of death. They are better trained, have access to sophisticated laboratories and technology, and they are more determined than ever to help find the answers to determine why a child, or other person, has died.

Death is creative. There are many physiological and developmental changes, particularly early in life, that leave a young child vulnerable. Statistics for child death indicate that more than 50% of all child deaths in the United States occur within the first year of life. While some feel that having that answer is a blessing, others feel it is a curse.

The Rational “Why”

The rational answer to “why” may be more complex and multi-dimensional. This may be where guilt, blame, and confusion ransack a person’s grief experience. The rational approach seeks to live and re-live the events leading to the child’s death, despite knowing the clinical answers “why.” If a child died of cancer, the parent may know, factually, the mechanism for death. But it’s the rationalization process of “why” that haunts them. They may retrace every bite of food, every trip to the ballpark, every family vacation trying to discover their own cogent answer to “Why did this happen?” “What did we do wrong?”

A parent whose child was killed by a drunk driver may rationalize that if they’d only have been home, or been away, or not asked their child to come at a certain time, or had only...then their child wouldn’t have been in the car and wouldn’t have died. While there may be crumbs of truth to this rationalization, the reality is that we cannot change the events leading to the child’s death and that ‘if only

we’d have known, we’d have done things differently.’ Even the parent whose child died for no determinable cause faces the gift-curse of rationalization. Many play a perpetual video recorder in their mind’s eye and change the course of events, thus altering the outcome of their child’s death.

One factor usually consistent with the rationalizing is the experience of the emotion; guilt. This process forces the human psyche to face changes in decisions which, perhaps, could have changed the final outcome. This very difficult realization evokes guilt in most parents, an emotion that is one of the most collective expressions of grief, yet one of the most debilitating (Kubler-Ross, 1989).

The Spiritual “Why”

Some families have a strong faith in an omnipotent entity, God. Some are uncertain. Others have no spiritual belief system.

Like the rational “why,” the spiritual “why,” may seem irresolvable, despite the diversity of people’s personal philosophies. Many people search their past trying to identify a transgression they committed for which now they are now suffering retribution. They didn’t go to church enough, didn’t spend enough time with their family, cheated on their income tax or their spouse. The mind can be a resourceful and imaginative enemy when death hits a family. Some families of strong faith find special solace in their belief system. Some say that they couldn’t survive the grief without it. Yet, others find their faith foundation even more challenging. They did everything they were supposed to do. They were faithful to their God, their morals, their principals, and still their child died. They may feel forsaken or betrayed and their entire relationship with God has been distressed.

Regardless of a person’s faith or absence thereof, most families still experience significant struggles with the spiritual question, “why.” This is the type of soul-searching event that can undermine every conviction and ideal a person held sacred.

Some parents ultimately surrender their faith when they can’t reconcile it with the loss they have suffered. Still some others will find their faith in the wake of their grief. The death of a child is a profoundly spiritual experience.

Grief’s Ego

The process of bereavement is a selfish one. A parent seeks information on “why” their child died. Immature in the process, they seek out others who have had duplicate experiences. Comparing grief is a normal reaction in the formative grief process. Because grief is all consuming, it is difficult to comprehend that anyone else in the world could be feeling the same way. The “why” paradigm (*fig 1*) holds some very basic truths within its realm.

Clinically, while parents struggle for answers, there is always doubt, even when a palpable answer is provided. Determining the physiological mechanism for death is important for many reasons. For families planning to have more children, understanding what really happened could be helpful in determining the potential for reoccurrence. And while some families find solace in knowing the clinical “why,” others feel that having the answer exacerbated their confusion about why their child died. There are no *real* answers and each situation is unique. Yet, grief’s ego can try to ‘measure’ the worst of the worst situations. “My child died of *thus and such*. There is nothing worse than that.” “Well, it is worse not knowing *why*.” “No, it is worse when it was *preventable*.” “It is harder because they were in *such* pain.” “She was my *only* child.” “He died in *someone else’s care*.” “He died in *my* care.” “I *never* brought her home.” “The house is not the same *without her here*.”

It is not unusual to hear these comments. Grief is arrogant, and rightly so. The horror of **all** these experiences is inconceivable. Yet, neither having a clinical reason why, nor the factor of preventability, nor the location, nor the age, nor the cause makes any child’s death more difficult

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than another. Every child's death is an equal tragedy which affects the family and the community.

From the rational perspective, blame and guilt are catalysts for destruction. The preventability, or perceived preventability of a child's death, can arise during this phase. When a child is in the care of the parents and then dies from an accident such as drowning, poisoning, or a fall while unsupervised, the parents are the hardest on themselves and each other. However, while guilt is a universal emotion of grieving parents, there is a corporeal guilt observed in the accidental deaths that can be insurmountable. These parents struggle with guilt, blame, and shame with self and society induced cause.

However, the reality of parenthood is that while as the ad says, "...it only takes a second (for a child to drown)," it is impractical to think that a parent can keep track of a child every waking, or sleeping, moment of every day. Most accidents are precisely that- accidents. Parents can only do their best to watch their children. Most do their job most of the time with great diligence. **But every parent has made a mistake.** Every parent has made that mistake (which usually does not result in a tragedy) and thought, "Oh no! They could have run into the street, or fallen into the pool, or swallowed those pills, or fell down those stairs, or I should have known they were depressed, I should have been watching them closer, I should have called more often..." The multi-agency campaigns to promote child health and prevent accidents can and do reduce the number of accident related deaths. But they also have a contraindication: Competent and loving parents who have lost a child to an accident, and not those guilty of criminal negligence, acutely rationalize the event and find themselves, often, unable to forgive a common mistake with a fatal outcome.

Understanding Grief the Why Overlap

There are three key concepts necessary to understand the affect of death on the human psyche: bereavement, grief, and

mourning. Bereavement is the social status granted to families experiencing grief. Grief is the manifestation of bereavement. It is featured emotions, inclusive of the "why" questions, of bereavement. From extreme sadness, depression, rage, and guilt, grief is the tangible expression of these emotions. The term 'mourning' refers to the grief work, that a person must experience to emancipate him or herself enough from intense psychological and physical bonds with the deceased child to return to day-to-day life and social responsibilities (easier said than done).

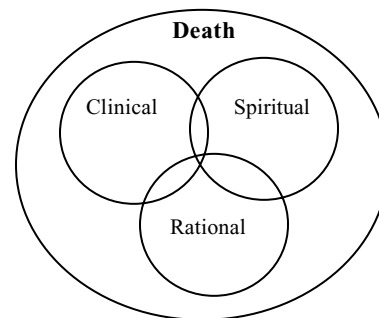
The death experience is saturated with diversion and silence and in our culture. We have socialized death, perhaps because of the historical shift from focusing on the after death events to the concern for the time preceding death. Most Americans face grief after the death of a loved one, though usually not their own child, alone and confused. Our culture has not kept up with the dramatic changes in how we die.

Decades ago it was not unusual for children to die, particularly during infancy. Many women bore six or more children recognizing that several will likely die. With the decrease in infant mortality, people began to expect their children to live. They had fewer and fewer children. More recently, couples are waiting until they are older to begin a family and on average have two children. Infertility is widespread. Thus, each child represents significant value to the family unit. It has become unthinkable for any person to die during infancy and childhood in our society. Most people cannot even bear to think about their own child's mortality and "it" becomes a topic that few dare to allow themselves to consider. These dynamics may propel the grieving family into an atmosphere of mystifying segregation from their core support system. The litany of misunderstanding surrounding parental grief is frequent concern.

The "Why" Paradigm

The clinical, rational, and spiritual questions play out during the process of grief. Most people experience an overlap of the

types of "why" questions. Soon after the child's death, most are focused on the clinical aspect of "why." This is the first thought, particularly in a sudden, unex-



pected death. Answers may seem to be an apparent means to closure and acceptance. Rationalizing helps the griever face the most debilitating emotions such as rage, guilt, and shame. This can be a necessary step toward healing. Dealing with those emotions can help the griever to develop and embrace coping mechanisms. The spiritual quest for answers can sometimes help the mourner with the 'unanswerables'- the enigmas to which only faith can provide comfort and support. This spiritual journey inward can be an epiphany for some, initiating life-lasting changes in a person's life - helping them appreciate their loved ones more, re-prioritizing, and gaining a new dimension to their approach to adversity and challenge.

Yet, each tiny step is excruciatingly painful for the grieving parent. There are a plethora of indescribable emotions and inconceivable thoughts. The most unshakable ones centering on "why."

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From the Heart of a Grandmother

In Memory of Aaron Lee Farrier

It's been four years since Aaron passed away
Four years in which I struggled everyday
I tried my best to carry on,
hide the heartache, stand up tall
Looking back on days I still recall...

I smiled when I didn't wanna smile
I laughed feeling guilty that I had
I lashed out at God and doubted faith
Then I turned around and prayed
he would help me through each day.

I spoke when I didn't wanna speak
I saw others' joy through jealousy
I listened but all I really heard
were well meaning empty words.
From those who did not hurt
and those who could not see...
That I'll never be who I used to be.

As I journey down grief's never-ending road
They will never know and I pray they don't
For time has now become my closest friend
And someday, in my own way, I will mend.

I'll smile thought it's only half a smile
I'll laugh and the guilt won't feel so bad
I'll listen and try to comprehend
Someday, we'll meet again

But for now, I must be content
And carry on... 'til then.
It's been four years since Aaron died.

Ros Hurley,
Grandmother of the Sunshine Boy

Passages 2001 *(continued)*

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kids in crisis, was on hand to perform for the children too! **Camp Paz** volunteers spent time playing at the pool, working through Kaleidoscope of Grief books, and making puppets, masks, and other crafts with the children who ranged in age from 5-15.

Friday evening ended with a touching candlelight memorial service with candles that were donated by the family of **Tony Lensen**, a five-year old who was killed in 1944 during a WWII school bombing. His sister and his mother donated the candles in his honor. MISS Foundation members gently called their children's names as they lit a candle to remember their beloved child. **Dr. J. Frederik Froen** also had an opportunity to light a candle for his nephew who was born still in Norway. The weekend was a poignant reminder that love is truly stronger than death.

The highlight of the event was the awards ceremony. The **Gold Wings Visionary Leadership Award** was given to **Dr. Michael Durfee** and **Jami Garrison**, MISS Foundation Board Member and web master, won the **Legacy Award** in memory of her mother, **Lois Ellen Miller**. **Ashlee Simps on**, age 10, won the **Giving Tree Award** for helping to illustrate our most recently released children's grief book and **Debra Scaturro** won the **Kindness Project Award** for her work with critically ill children and humanitarian efforts. Two outstanding health care workers, **Dr. Guillermo**

Guiterrez, Neonatologist at **Phoenix Children's Hospital** and **Linda Schill, R.N.** at **Thunderbird Samaritan**, won awards for their compassionate care to families who experience child death. Two corporate awards were given to the **Glendale Active 20-30 Club** and **United Parcel Service (U.P.S.)** for their support and volunteerism to benefit the MISS Foundation.

The conference closed on Saturday afternoon with a brief reception and raffle. On display at each event was the MISS-ing Angels quilt, an interwoven masterpiece of hundreds of square representing hundreds of lost lives that was lovingly created by **Kym Smith, Donna Howell**, and **Janine Armstrong**.

I'd like to thank the entire **Board of Directors** and our committed **facilitators** and **volunteers**. Without you, this would not have been possible. There are no words that can express how truly grateful I am. And I shall close with comments from the evaluations submitted by families touched by the death of a child:

Comments from participants included: "Thank everyone for everything. It was the most wonderful experience I have ever had and I will never forget the people and presenters I met."
G.P., Argentina

"It was such an amazing conference. I learned so much...this is the most incredible organization and people I have ever encountered! You've made an im-

pact on me that will last a lifetime!" L. G., Tempe Fire Dept.

"This has given me a new calm and peace in my life. I feel like I can begin to work through my grief now. Thank you so much!" A.N., Parent

"A wonderful, beautiful, peaceful time."
K.H., Parent

"You cannot imagine how much this has helped me. Thank you so much! The speakers were wonderful, the location was great (well, it was a little hot) and the candlelight was incredible. Plus, Dr. Kubler-Ross being there was such a surprise." S.J., R.N., New York

"Last nights session helped me more than imaginable. You made me see there are other people that know how I feel...You opened a whole new world for me. I am deeply touched by your foundation and the people. I was able to let all my feelings come out through tears...Thank you so much!" P.S., Age 14

We'd like to thank our key sponsors again: St. Luke's Health Initiatives, Banner Health Systems, Samaritan Healthcare, Southwestern Litho, Lufthansa Airlines, Phoenix Police and Fire Departments, and Rural Metro Fire Department for their support. And, once again, thank you to our endless list of volunteers, presenters, and board members who helped make this conference one that will be etched in our hearts always.

A Lifetime of Giving: Time to Reflect on the Wings of Elisabeth

Dr. Elisabeth Kubler-Ross Elected Honorary MISS Foundation Board Member

In a rare public appearance, Dr. Elisabeth Kubler-Ross received the Platinum Wings Lifetime Achievement Award for her service to humanity. The awards speech left many awestruck in the room, for every person realized they had been touched by the wings of an earth angel. The speech and presentation was given and read by MISS Founder and friend of Kubler-Ross, Joanne Cacciatore:

“Each year, the MISS Foundation honors an individual with the Platinum Wings Lifetime Achievement Award. This is an exceptional award intended to recognize a person who has given their lifetime to helping change our world, and taking us, step by step, toward the betterment of humanity. Let’s pay tribute to her and share some of the reasons she was chosen as we travel down the pathways of her life:

Reading excerpt from Death: The Final Stage of Growth
It is hard to say if my precarious introduction to life was the first “instigator” to going into this field. After all, I was not expected to live and if it had not been for the determination of my mother, I might not have survived. She strongly believed that such little infants could only survive if they received a great deal of tender loving care, frequent breast feedings and the warmth and comfort that only home could give... She cared for the three of us person-

ally, nursed us every three hours... So perhaps the first significant lesson in my life was that it takes only one human being who really cares to make a difference between life and death.”

Born one of triplets at just 2 lbs, she may have been tiny, but she has proven, even until this day, to be one of the mightiest women in history fighting against Goliath-sized forces of ignorance, hatred, and fear.

Since her tender teens, she has been an activist for empathy and compassion. Courageously fighting Nazi terrorist activity, she worked with the victims of WW II and treated refugee children who survived the horror of the concentration camps.

Reading excerpt from The Tunnel and the Light:
“I ended up in Maidanek in Poland, in a concentration camp where I saw train loads of baby shoes of murdered children, train loads of human hair. To read about this in books is one thing, but to stand there and see the crematories and smell it with your own nose is something quite different...I asked myself: how can grown men and women like you and kill 960,000 innocent children and at the same time worry about their own children at home having chicken-pox? And then I went to the barracks where the children had

spent the last night of their life... Maidanek was the beginning of my work.”

In 35 years of devoted service, she has never charged a single patient. For many years, she specialized in helping children who were terminally ill- many with cancer. Instead of ignoring the child and reality, she patiently communicated with her dying patient and offered real solace, respect, and comfort. A true international citizen, she traveled around the world, making house calls in remote villages, dedicating her life in the service of helping others in the most difficult circumstances.

Reading excerpt from The Tunnel and the Light:
“She had opened the door to the hospital room and there was this mother in a coma...a picture of total loneliness. Nobody touching. The two little girls dashed into the room, jumped up on mommy’s bed...they shared with mommy that they knew she could not hug them anymore, but that she could hear every word they said and that very soon she would be as free as a butterfly. The father naturally started to sob and cry and finally hugged his children and communicated with them. The next morning, Lorrie went to class to ‘show and tell...’ She went to the

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A Star in Heaven



We sit beneath the night sky
 By the whisper of windsong...
 In the quiet of the darkness.
 And they are never far.
 Those we have loved
 and cherished,
 Those who have changed our lives
 In some small or profound way
 Are closer than we know,

Because it is their light
 That shines on our world.
 It is the brilliance of their souls
 That makes our night sky glow
 A star in heaven shines
 Just for you...

MISS Foundation’s **Sacred Hearts**
 Logo Pendant ~ A Beautiful and Unique Gift
 Representing Eternal Love
 Custom Made Sterling Silver Pendant with
 20” chain now available with or without
 birthstone (see order form page 22)

\$60.00

Add \$12.00
 For birthstone and
 specify month



Elisabeth *(continued)*

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blackboard and drew a cocoon and a butterfly coming out of the cocoon and shared with her class of first graders her visit to her dying mommy in the hospital and thus gave what we considered the first Death and Dying Seminar to a class of first graders by a first grader... Because of this one shared moment with her mother, this child was able to reach the whole class..."

She brought the first hospice to the United States. And as a medical doctor, she was often surprised by the disconnectedness between the doctor and patient- an unwillingness to share and communicate, honestly, and about the plethora of emotions the patient or the surviving family faced. She spoke out within her own discipline to change the ethos in medicine and encouraged physicians to interact on a deeper, psychosocial platform with their patients. She became a tenacious advocate and an immutable voice.

Reading excerpt from On Children and Death (This is the first book I read after Cheyenne's death in 1994)
"No one can successfully shield another person from the pains of life; no one can take our grief away. No one can truly console a parent who has lost a child or make the grim reality disappear. But we can help them and

be available to them. We can be there when they need to talk...cry...when they have to make decision to difficult or complex to decide on their own... In Laura's case, the depression started long before the tragic death of her baby before the delivery...her physician avoided her...she was sedated and unable to grieve, unable to experience the depth of her pain, and thus unable to start living again."

With undying fortitude, she has faced her share of adversity too. Her farm home was burned to the ground. Lost were all her possessions, priceless memories- photographs- journals of her past- research- she had lost it all. She had planned to adopt eleven AIDS-infected babies into her home. Ignorance, prejudice, and arson would interfere. This tragedy brought her to Arizona in 1994.

She has touched you, whether you know it or not. She is the single most influential force in changing the perception of death, dying, and the culture of grief, introducing the subject as discourse now mandated in most medical schools and universities. It is impossible to have been born after 1960 and remain unaffected by her work.

The day I first met her, I was supposed to spend an hour or two with her. I was mesmerized for 5-1/2

hours. There was tremendous love, compassion, and truth in her presence. And even though her physical cocoon is weakened, her spirit is compelling and valiant. And she continues to inspire us all with her own words from her book *The Wheel of Life*:

There is within each of us a potential for goodness beyond our imagining; for giving which seeks no reward; for listening without judgment; for loving unconditionally.

I am very proud to present the Platinum Wings Lifetime Achievement award to my hero, my mentor, and beloved friend, Dr. Elisabeth Kubler-Ross."

And with tears streaming down her face, Honorary Board Member, Dr. Elisabeth Kubler-Ross, was escorted to the front of the room by her son to accept the award. The standing ovation lasted several minutes as many people shared the emotions of Kubler-Ross. Then several hundred people joined in unison to sing "Happy Birthday" as she was presented with a hand crafted silver necklace of the MISS Foundation's logo embedded with her ruby birthstone. As she put the gift around her neck, the audience realized that this moment in time was a miraculous one to remember and share with their children and grandchildren.



Dr. Mark Fischione gets to know attendees at the First Annual MISS Foundation Conference: Passages 2001.



Joanne Cacciatore presents the Platinum Wings Lifetime Achievement award to friend, Dr. Elisabeth Kubler-Ross