



When a Child Dies: Spiritual Struggles and Solace

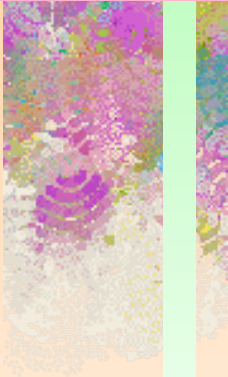
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Angels of Mercy

by artist Brian Andreas



Most people don't know that there are angels whose only job is to make sure you don't get too comfortable & fall asleep & miss your life



Objectives

- Spiritual stages of grief
- Common “big questions” parents ask
- Various paths and resources for seeking answers to the big questions
- Spiritual lessons families have learned



Terms/Language

- “Spiritual” and “God” used very broadly
- Not necessarily connected with organized religions or institutions



When a Child is Dying

Award-winning educational film produced by Beth Seyda and Erica Rothman

- **Debra struggles with her spiritual/religious beliefs during the illness and death of her son, LeRon**
 - Traditional religious background, belonged to faith community, and regularly attended church
 - Hid Bible and stopped praying
 - Angry at Christ and gave Him a piece of her mind
 - Started reading the Psalms again
 - Religion was outside (e.g., gardening)
 - Life could still be abundant without LeRon



Spiritual Stages of Grief

- **Anger:** turning away from God, not participating in a faith community
- **Working through the Anger:** actively searching, religious obstacles
- **Reexamining Faith/Rethinking God:** change and new ideas



Dylan's Life and Death

- After 12 years of marriage and 6 years of trying to get pregnant, learned from 16-week ultrasound that baby had birth defect and only 50% chance to survive
- Prayed, but to no one in particular
- Did not have Dylan baptized (not required to get into Heaven in my book)
 - Assured him that he would be surrounded by family/friends in Heaven
- Asked Dylan to give us a sign that he was OK
 - Penny and Pachelbel





Asking “the Big Questions”

- **WHY** -- why did my child have to die? Why did my child/family have to suffer?
- Are we being punished? (*Did my child die because I did something bad?*)
- Where is my child now? Did s/he go to Heaven? (*Is there an afterlife? Is my child safe?*)
- Will the pain ever go away? How can we go on? (*What will my life be like now?*)
- Do we want another child? (*What if our next child dies?*)



Seeking “the Big Answers”

- Books Beth read:
 - *Conversations with God (Books 1-3)* and *Friendship with God* by Neale Donald Walsch
 - *The Celestine Prophecy* and *The Tenth Insight* by James Redfield
 - *Embraced by the Light* by Betty J. Eadie
 - *A Grace Disguised: How the Soul Grows Through Loss* by Gerald Sittser
 - *Angelic Presence: Short Stories of Solace and Hope After the Loss of a Baby* by Cathi Lammert and Sue Friedeck



Seeking “the Big Answers”

- More books Beth read:
 - *Waiting with Gabriel: A Story of Cherishing a Baby’s Brief Life* by Amy Kuebelbek
 - *The Laws of Spirit: Simple, Powerful Truths for Making Life Work* by Dan Millman
 - *Tuesdays with Morrie* by Mitch Albom
 - *The Seat of the Soul* by Gary Zukav
 - *Synchronicity as Spiritual Guidance* by Mark Thurston
 - *Journey of Souls* and *Destiny of Souls* by Michael Newton



Seeking “the Big Answers”

- And more books Beth read:
 - *Empty Cradle, Broken Heart* by Deborah Davis
 - *Transcending Loss: Understanding the Lifelong Impact of Grief and How to Make it Meaningful* by Ashley Prend
 - *Writing to Heal the Soul: Transforming Grief and Loss Through Writing* by Susan Zimmermann
 - *When Bad Things Happen to Good People* by Harold Kushner



Seeking “the Big Answers”

- Additional resources:
 - *A Grief Observed* by C.S. Lewis
 - *When a Child Dies* by Carol Prgent
 - *Lament for a Son* by Nicholas Wolterstorff
 - *Psalms of Lament* by Ann Weems



The Journey

- Evolution

- Initially would do anything to have Dylan back
- Then could recognize positive changes in self and how was approaching life differently
- Not either/or, accept both -- Dylan's spirit is always with me and I am living life more fully



Aha! Moments* Along the Way

- Murphy Brown -- final show (5-22-98)
 - Murphy had breast cancer in the final season and in a dream sequence, Murphy interviews God (play by Alan King)
 - “your illness was a gift”
 - “use your work to make a difference”
- ER -- season final show (5-20-99)
 - Jeannie Boulet, HIV positive PA, talks to a friend
 - “maybe what happened today didn’t happen *to* you, maybe it happened *for* you”

* courtesy of O, The Oprah Magazine



Spiritual Lessons

- Bereaved Mom after premature twin daughter died:
“Nothing is guaranteed, life is precious. Tell people I love ‘I love you’ every day.”
- Bereaved Mom after teenage son died:
“Look at the world totally differently. Appreciate things a hundred thousand times more, very simple things.”



Lessons Learned

- Love never dies
- Be present, in the moment
 - Pay attention to life
 - Live life passionately (don't just go through the motions)
- Compassion
 - Better understand pain and suffering
- Gratitude
 - Appreciate small things
 - Focus on what have vs. not have



More Gifts from our Children

- Inspired by child's courage
 - Examine own fears
- Focus on what's really important
 - Don't sweat the small stuff
- Balance head and heart
- Beauty of the circle of life
- Teach what you have learned
 - Live by example



Open Heart

by artist Brian Andreas

He told me one time he forgot himself and his heart opened up like a door with a loose latch and he tried for days to put it all back in proper order but finally he gave up and left it all jumbled up there in a pile and loved everything equally



My Answers to “the Big Questions”

- Why did Dylan have to die? ***That was the plan -- Dylan’s life and death provided opportunities for spiritual growth (for him and us) and to improve care for children/families.***
- Are we being punished? ***No!***
- Did Dylan go to Heaven (and by the way, where is Heaven and what is it really like)? ***Yes. Heaven is so close you can almost touch it and it’s awesome.***
- Will we ever heal from this heartbreaking experience? ***Yes, but healing will be a lifelong journey.***
- We want another child, but will we be given another chance? ***Yes, after a miscarriage we had Tyler (now 7 years old).***



Supporting Families

- Acknowledge it's normal to question spiritual/religious beliefs
 - Why did God allow this to happen?
- Journey with the family -- allow them to go through spiritual stages of grief
 - Uncertainty is challenging
 - Religion may/not provide comfort
 - Institutions may foster blame and guilt
 - Be wary of those offering “the solution”



Supporting Families

- Discuss issues with “spiritual care” counselor
 - May be a religious person/clergy
 - Needs to be open to/support the journey
 - Good listener
 - Uncover real concerns behind the questions
 - Offer options/resources



Zen Cards by Daniel Levin

Understanding

What happens to you does not matter: what you become through those experiences is all that is significant. This is the true meaning of life.



Contact Information

For more information about the award-winning educational film, *When a Child is Dying*, the accompanying *Supportive Care Handbook*, workshops, conducting research, or developing educational/ supportive resources, please contact:

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