

Out of the Darkness

Supporting Parents and Caregivers
Following a Pregnancy Loss or the Death of an Infant or
Young Child

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Death of a Child

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I loved you
like there was
NO TOMORROW . . .

and then
one day,
THERE WASN'T.

~ author unknown



**The
Compassionate
Friends**
Supporting Family After a Child Dies

Statistics on child death

- According to the WHO, in 2013, 6.3 million children under the age of 5 died around the world. Nearly half within the first month of life
- In 2011, 44,226 parents in the United States lost a child under the age of 19. Nearly half of those losses were children under the age of 1 year.
- According to the Children's Defense Fund, Every Day in the US
 - 4 children die as a result of abuse or neglect
 - 5 are lost to suicide
 - 7 are killed by guns
 - 24 die from accidents
 - 66 babies die before their first birthday

Bereaved Parents are everywhere

- Every single day in the United States, over 120 parents lose a child under the age of 19!
- This does not count babies not yet born or adult children over the age of 19.
- ALL of those parents are thrown into a world they never expected to be in and certainly don't want to be a part of.
- Yet, they have no choice. They are indoctrinated into a club they never wanted to join and can never leave.
- They have no map to guide them. No frame of reference. No idea how to navigate this horrible storm.
- *NONE of them expected "it" would ever happen to them.*

Thinking the unthinkable

- For some people in this room, and perhaps many of you, this has been your reality. You are a bereaved parent. You know the pain of such a profound loss.
- Simply being here is a powerful trigger. I acknowledge that and hold you and your child in light and love.
- If you have not personally suffered the loss of a child, take a moment to think of someone close to you who has. Imagine, for a moment, this was your reality. How do you think you would react to the news? How would you want those around you to support you? What would you find helpful? What would tick you off?
- Part of the reason it's so hard to find support after we lose a baby or child is because people don't want to talk about it for fear it could happen to them, or they can't imagine being in our shoes. They are afraid. They are too uncomfortable around our pain. They don't know what to say so they say nothing. They are afraid to make us cry or upset, or that they will cry. Afraid to make us think of our child and our pain. Fear is powerful.
- We had no choice... it changes your perspective... on life, on death, on *everything*. *It changes the very core of who you are. Part of your identity is now that of a bereaved parent.*

Out of the Darkness...

There is no greater loss than that of a child. It does not matter how old the child was or the circumstances of their death, a parent's grief feels unbearable.

Whether you are a bereaved parent, family member, or, perhaps a friend, co-worker, or professional who works with the bereaved, this book was written for you. A source of information, support, resources, and strategies for coping and healing.

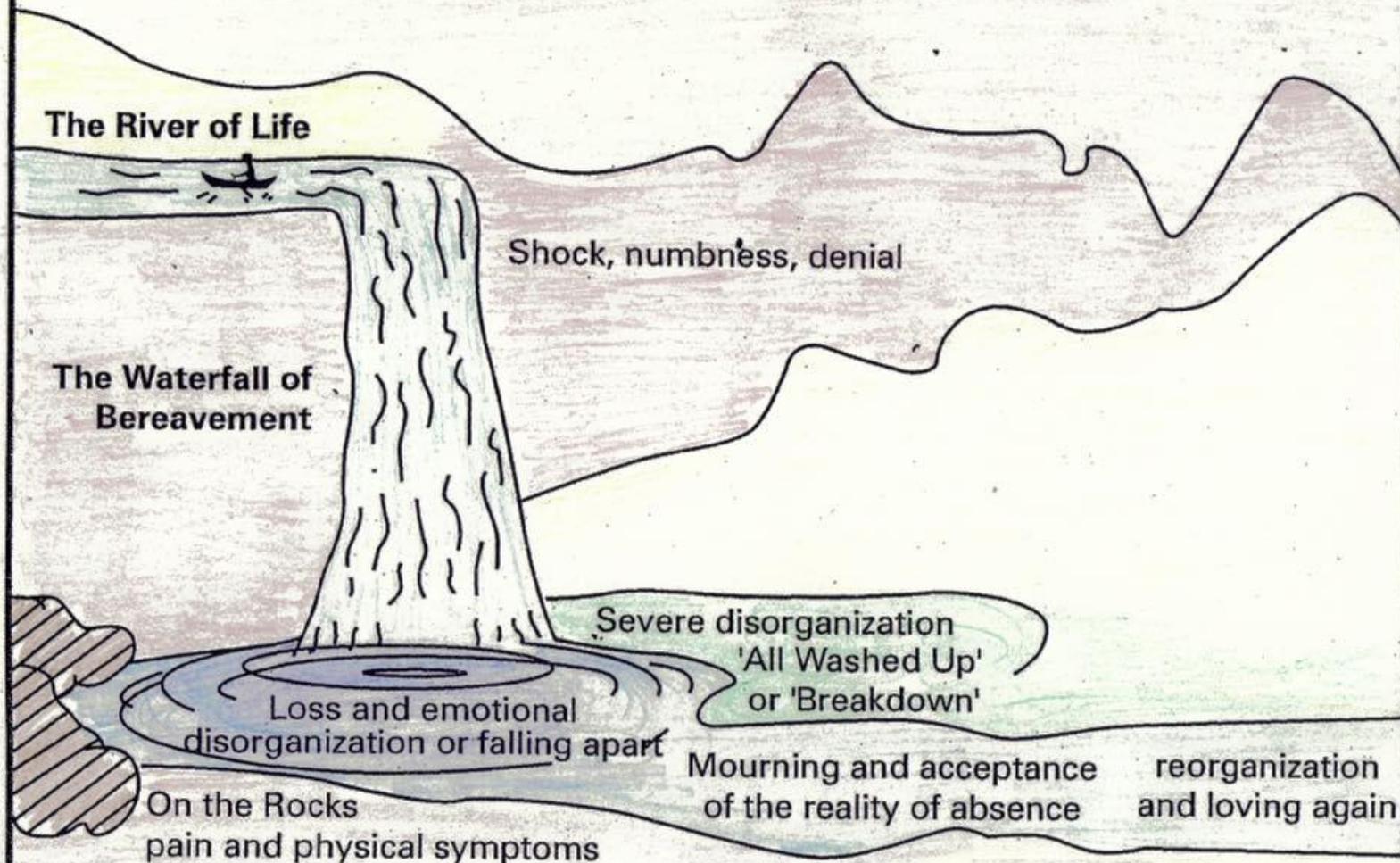
It's like having your own personal grief mentor. A personal guide, to walk with you along the path.

Wherever you are in your grief journey, you will find valuable information in these pages. You will find your way out of the darkness and into a place of color and light again, where you will weave your child's memory into the fabric of your life and hold them in your heart forever.

Grief 101

- Grief is the reaction to a death/loss or anticipating one. We grieve the death of a loved one, but also the end of a relationship, a job, and other losses.
- Profound grief is often referred to what occurs with a traumatic, unexpected death of a young child, spouse, or parent.
- Most importantly: *There is no right or wrong way to grieve the loss of a loved one. Only your way. It's a journey. A path you can walk WITH someone but not for them.*
- No two people grieve the same way. Parents often grieve very differently from one another

THE WHIRLPOOL OF GRIEF



Bereavement is what happens to you; grief is what you feel; mourning is what you do.

A parent's grief: the most profound

- You lose not only a child, but all the hopes and dreams you had for that child and the way you envisioned your family and your life. You lose your identity as of that moment and step into a new one. You are forever changed.
- It's not the natural order of things.
- You may lose the opportunity to parent THAT child, possibly the loss of the ability to have biological children and even grandchildren.
- Losing a child is a tremendous stress on relationships.
- There will be secondary losses for many bereaved parents.
- You don't ever "get over" the death of your child. It's a journey that lasts a lifetime.
- Triggers are a lifelong reality, but much more common and unexpected in the first year or two.
- Grief changes over time, but you will never forget your child's life, their death, and the impact those experiences had on you. Research shows many parents grieve indefinitely, even with "positive adaptation"

"The reality is that you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but, you will never be the same. Nor should you be the same, nor would you want to."

— Elizabeth Kubler-Ross
and John Kessler

A cultural and societal problem

- We don't "do" grief well
- The general population's grief I.Q. is pretty low, largely because no one likes to talk about death
- Few people know what to expect, or what they are supposed to feel, or if what they are feeling is normal or not, yet they often don't ask and are not told.
- The death of a child is every parent's worst fear. No one wants to talk about it or even think about it happening to them.
- Talking about death, especially of a baby or child, makes others very uncomfortable and they often avoid talking about it or to bereaved parents because it makes THEM uncomfortable.
- Very little is known about options and choices when it comes to death and the rituals associated with it – until you are forced to have to make those decisions

The emotions associated with grief

- Shock and numbness
- Denial – refusal to believe their child has died
- Anger
- Bargaining
- Depression/ profound sadness
- Acceptance or integration

There is no order or time frame for these emotions. It's a roller coaster. They ebb and flow like waves on the ocean.

Other common initial reactions

- Illogical behavior
- Throwing their attention to work or other children
- Difficulty processing and understanding information
- A need to tell the death story
- Impaired decision making
- Impaired memory
- Forgotten responsibilities
- Uncharacteristic behavior
- Forgotten items of general safety (left stove on, garage open, fire in fireplace, water running, doors unlocked, etc.)

Anticipatory Grief vs. Sudden Grief

- Anticipatory grief
 - Terminal illness or life limiting illness
 - Choosing to remove life support
 - Knowing your baby has a defect incompatible with life outside the womb or not expected to survive long after birth
 - Knowing your baby has died in utero, before labor has begun
 - Elective pregnancy termination
- Sudden or unexpected grief
 - Unanticipated stillbirth
 - Infertility
 - Miscarriage
 - SIDS
 - Accidental death
 - SUDC – sudden unexplained death in children
 - Homicide/suicide
- Is it better to be “prepared?”
 - Pros – chance to say good-bye, prepare for the eventual death, control
 - Cons – can be emotionally exhausting and prolonged

What it's like to be told your child has died

A parent's experience is impacted by how they learn of their child's death

- How they were told
- Who told them
- When and where they were told
- Who they were with, or, if they were alone
- What support or other information accompanied the news
- If they need to identify their child
- How their deceased child was presented to them and how well prepared the parents were for what to expect (tubes, clothing, machines, what the room looked like, what their child would look like, feel like, etc.)
- A word about media/social media

For caregivers who deliver the news

- Prior to death, if possible, deliver information incrementally and honestly.
- Do not give false hope.
- Try to be at their level physically. Sit next to them or across from them. Try to avoid standing if they are not also standing. Offer for them to sit if they are standing before delivering the news.
- Use the child's name when speaking to the parents
- Speak slowly and in simple, short sentences, allow time for the information to sink in
- Use simple language, avoid medical terms and jargon with or around the family
- Avoid using euphemisms for death "better place", "gone", "with God", "sleeping with the angels", "Gone to Heaven", even with siblings or children. Use the terms "died", "death", or "dead". Use instead, "I'm so sorry, we did everything we could, but _____ has died."
- Offer to allow the family to see their deceased child and spend as much time as possible with them. Prepare them for what they will see/hear, and what their child looks like and for how long they will have with their child.

For the caregivers who deliver the news

- Try to make eye contact with all family members present. Not just the ones who are conversing with you
- Look for and use non-verbal communication. A gentle touch to the arm or shoulder.
- If anger is directed at you, try to simply accept it in the moment. It's likely a grief reaction. If their anger/accusations are grossly in error, attempts to educate gently with compassion (I understand how difficult this is and that you are angry..."), but it can also be addressed at a later time
- Remain with the family as long as you need to for them to absorb the information and ask questions
- Be comfortable with sitting in silence and holding the space. Your presence can be most reassuring and helpful. Unless they directly dismiss you and ask you to leave.
- Remember, you cannot remove or change their pain and apparent suffering in the moment. Accept their pain and whatever expression of it they show
- Do not attempt to offer any "silver linings" or platitudes. Avoid offering philosophical, religious, or spiritual based concepts. If the family offers them, you may nod or verbally share their sentiment if you wish, but don't offer it.
- Express that you are so very sorry for their loss. Offer your availability should they have any questions at a later time.

A glimpse into the pain

A must read for anyone who works with bereaved parents. To understand THEIR experience, their behavior, and what you can do to help.

- Be With Me. Just for Today
 - The first chapter of my book [Out of the Darkness](#)
 - Also in a blog at <http://lovelightlaughterandchocolate.blogspot.com/2012/12/be-with-me-just-for-today.html>

"I loved you from the moment
I knew you were there,
and you will be loved
until the day I die"

Zoe Clark-Coates

Emotional responses to the news your baby or child has died may include:

- Shock and disbelief
- A foggy feeling, like it's surreal, a bad dream, that it is not really happening
- Profound despair
- Mournful crying or wailing
- Complete detachment, shutting down emotionally
- Anger – usually externally directed. At their medical caregivers, their spouse or SO, someone they perceive directly involved in their child's death, God or a higher power, even at their own child for dying
- Guilt – a feeling their child's death is somehow their fault, if only they said or did something different
- Memory loss and confusion
- A desire to die yourself

Emotional reactions of bereaved parents

- They may want to see, touch, hold, and spend lots of time with their deceased child
- They may not want to see their deceased child at all, or, may attempt to, but run out of the room
- In the case of needing to identify their child, they may need to send someone else or be accompanied by others for support
- In the case of a pregnancy loss, decisions to be made about the birth and postpartum can feel overwhelming, with an inability to make decisions or a desire for others to make decisions for them or be “knocked out”.
- In the case of miscarriage or stillbirth, feelings of isolation and disenfranchised grief are common - their baby’s life is not always acknowledged as important by friends and family, sometimes even by professional caregivers. Especially after a few days.

There is no foot
too *small*
that it cannot leave an
imprint
on this
WORLD.



Physical manifestations of grief

- Chest pain
- Difficulty breathing
- Feeling dizzy or even passing out
- Feeling “heavy”, like it’s difficult to move
- Feeling shaky or weak
- Nausea or vomiting
- Abdominal pain – as if you were punched in the gut
- Collapsing
- Wanting to run away
- Inability to cry or make words come out right or at all
- Uncontrollable crying, yelling/cursing or uncharacteristic physical outbursts (punching walls, throwing things)

The weight of grief



Rituals around grief and loss

- Must take into consideration and honor personal, cultural, and religious beliefs and traditions. Ask!
- Rituals are for the survivors, but the parents' preferences should be explored and choices given to them, *not made for them*.
- Provide information and opportunities for support and sharing. Don't decide for them when to give them this information. You don't know how they feel or what they want. Let them decide!
- Give structure and order to the incredibly difficult hours and days after the death of a baby or child
- Celebrations of that child and their life, however short
- Show the parents that they have a village and their village cares about them

Helping parents pre-death

In circumstances when a child has a terminal illness, has died in utero or is not expected to survive birth, has a life-limiting illness, or parents are faced with a decision to terminate life support

- You can provide support and information/resources to help them prepare and make difficult decisions
 - About what is important to them for this baby or child's birth and or death
 - Organ donation possibilities?
 - Who and what do they want there (or not want)
 - Religious rituals that are important? Last rites? Baptism? Blessings?
 - What do they envision the environment to be like?
 - Where do they want it to happen (home, hospital, somewhere else)?
 - What they can expect to happen, how long it may take, what can be done to ease any pain or suffering for all involved?
 - Do they want photos (NILMDTS), music, stories, hand and foot prints? Help them get those things together.
 - Provide information about what happens after the death, what arrangements need to be made, offer to help them start that process if they wish
 - Breast milk donation? (Mother's Milk Bank Northeast)

What you can do

- Prepare the parents for what might happen as the child nears death and at and around the moment of death, as well as what can be done to facilitate comfort for both the child and the parents.
- Give the parents permission to change their mind at any time. Let them know you are there for them, anytime, for any reason.
- Facilitate their desires when the time comes, anticipate their needs. Doula them.
- Offer support. Hold the space. Listen. Reflect. Love.

“We cannot step inside their shoes and feel what they are feeling, but we can become curious, enter into their story, and honor their need to grieve as they choose.”

Jane Heustis and Marcia Jenkins

Companioning: Dr. Alan Wolfelt

Center for Loss and Life Transition

- Be present in their pain, don't try to take it away
- Bear witness – honor the experience, no judgment
- Don't try to fix – go with them, don't try to lead them out
- Cultivate an open heart
- Let them lead and teach you, walk alongside them, don't try to teach them
- Respect disorder and confusion – don't impose logic
- Be compassionate and curious, not the “expert”
- Listen with the heart, don't analyze with your head
- Sit with them in their “hell”
- Discover the sacred gifts of silence, don't fill it with words
- Use active and reflective listening, listen for words that come with emotion, repeat those words back to them and use “tell me more”

It's your road, and yours alone.
Others may walk it with you,
but no one can walk it for you.

~Rumi

Immediately after a baby/child dies

- Photos of the birth or of the child/baby with parents, siblings, grandparents, alone, with important items like parent's wedding rings, special keepsake items like a teddy bear or lovey.
- Keepsakes like hand/foot prints, locks of hair, plaster hand/foot molds, hats, clothing, or blankets
- Bathing the child and dressing them
- Naming of the child, saying their name
- Religious or cultural rituals, prayer, playing a special song
- Be available but not intrusive. Offer guidance if the parents seek it or seem unsure. Give them permission to touch, hold, kiss, rock, dress, bathe, and love their child as long as they need to or want to
- Offer them the chance to take the baby home, perhaps even have a home funeral or wake (cuddle cots)
- Avoid comparing their child's death to any other death experience
- Be an active listener. Hold the space. Be with them, wherever they are.
- Love.

What about siblings and grandparents?

- Grandparents have a double grief. They grieve the loss of their grandchild AND the for the pain their child is experiencing
- Siblings should be allowed to be involved to the extent they are comfortable with.
 - Give them age-appropriate information
 - Be truthful, use concrete terms
 - Allow them to ask questions and answer them honestly
 - Allow them to participate and be present, but don't force them, they are amazingly self-limiting
 - Arrange for child care to “back up” or help the parents during the first week and as needed, especially for the rituals

Meaningful memories







Ornaments



Rituals that need to be planned

- Happen while still in the shock and numbness stage most often – first 24-48 hours after the death.
- Parents are nearly incapable of making decisions or truly informed choices at this time, but they should still be given the information and opportunity.
- Others are reluctant to give them choices so as not to overwhelm them, but then they may not realize they have choices and later have regrets!
- Autopsy may be required or it may be optional – this can be very traumatic for the parents.
- Funeral directors can be a tremendous source of information and support, but choose carefully.
- Many of the rituals associated with death and mourning in our culture are expensive! The average funeral costs around \$8000. Obituaries alone can cost over \$200!

Rituals

- Choosing a funeral home vs. a home funeral
- Choosing to write an obituary or birth/death announcements
- Prayer or memorial “cards”
- Choosing for a private or public wake or visiting hours
- Choosing cremation or burial
- If burial, choosing a casket
- Choosing a funeral service or memorial service – what do they want to happen at the service? Music, readings, photos/slide show, participation, etc.
- Choosing flowers and/or a fund/charity to donate to in memory of
- Choosing a burial place (rules!) or choosing an urn or keepsake container if cremation is chosen and burial is not.
- Choosing a headstone or grave marker if burial is chosen. It can take months for it to arrive!

Out of the ordinary ideas

- Consider photographing the funeral, calling hours, other important moments. They can make important and cherished keepsakes, especially for siblings who are too young to remember and even for the parents, who may not be able to remember because of the way grief impairs memory.
- Display a “tree” and tags/cards people can write thoughts and wishes on or a guest book that encourages more than just a name. For a child, a photo of the child and a book or signing mat for people to write their favorite memories in.
- Consider a home wake/funeral if allowed or just keeping the baby/child at home for a few hours or even days. A funeral director can help with the logistics. (Recommend “Ghost Belly”)

Birthday cupcake picnic





Unexpected Challenges After a Child Dies

- Dealing with media
- Grief keeping on social media
- Answering the question “How many children do you have?”
- Coping with triggers
- Secondary losses
 - Friends
 - Changes in relationship with spouse or SO
 - Loss of desire to participate in events where you are reminded of your pain/loss
- Financial burdens
 - Medical bills
 - Funeral/memorial expenses
 - Those related to loss of income

Triggers

- Emotional episodes that happen out of the blue and often can change the mood of the parent like a switch
 - Seeing a child that resembles theirs, or a pregnant woman if a pregnancy loss
 - Hearing a certain song
 - A sudden memory
 - Hearing a similar story to yours
 - If you've lost a newborn, seeing other newborns (likeness triggers of all kinds)
 - Going to or driving by the same hospital where the child was born or died
 - A postpartum visit or pediatrician visit with a surviving child/sibling

Signs of difficulty in coping

(that persist and are interfering with daily function after several weeks/first few months)

- Turning to alcohol “drowning the sorrows”
- Excessive medication usage
- Acting out of character frequently and persistently
- Excessive risk taking or a change in behavior uncharacteristic of the person
- Severe change in eating habits that persists with significant weight loss/gain
- Profound depression
- Increased anxiety
- PTSD
- Suicidal ideation

What grieving parents need

- To know you care about them AND their deceased child
- To acknowledge their child's existence and importance in their life. *Say their name. Talk about them. Share memories.*
- To ask how they are doing. AND listen to what they say.
- Unconditional love and support
- Truthful information
- Resources. Let them decide when and if they will use them, don't make those decisions for them. Provide books, websites, articles, information on support groups as soon as you can.
- To know you are there for them. Anytime. Anywhere.
- For you to not give up calling them, checking in , or offering to visit, bring food, or help, even when they don't pick up the phone or call them back.
- To know what they are experiencing and feeling is normal. That they are not alone.

Sometimes when I say
"Im okay",
I want someone
too look me in the eyes,
hug me tight and say,
"I know you're not"

How to help a grieving family

- There are things you can DO to help
- There are things that are helpful to SAY
- There are things that are NOT helpful to say or do

Remember, it's about them not about you! No matter how uncomfortable you are, their child has died. The world as they knew it has ceased to exist. They have no choice in "going there".

Please, do not...

- Do not touch or move ANYTHING in the home, especially if it has to do with that child.
- Do not clean that child's room, do laundry, vacuum, wash the dishes they may have used...
- Do not assume you know what the parents need or want.
- Do not make suggestions to them or tell them what to do or not do unless they ask you to, and even then, re-direct the question back to them.
- Do not make decisions for them.
- Do not tell them how they should feel or not feel, act or not act, or what to do or not do

Ways to help

- Provide resources and factual, practical information about what they can expect to experience and feel
- Ask open ended questions and be an active listener
- Be with them, wherever they are
- Offer hugs, share their tears and their laughter
- Don't tell them how to feel or act, or what they are feeling or doing is somehow wrong "You shouldn't feel that way! It's not your fault"
- Help them plan for the rituals of death by discussing what is important to them, if they are ready and willing. If they can't, ask if they'd like your help.
- Set up a meal train or friends/family to assist with household chores, shopping, or watching other children
- Start a fund to pay for funeral expenses or scholarship fund with a local bank or Go Fund Me account
- Gift them a meaningful memorial keepsake

Other ways to help

- Offer to help address thank you cards
- Offer to do shopping, laundry, household tasks, or drive places so they have company
- Offer to make any phone calls that need to be made
- Recognize everything has changed. Don't pretend that it hasn't or will ever get back to "normal" for them
- Invite them to dinner or bring a meal
- Send a card, text, or email randomly to let them know you are thinking of them. Especially on the difficult days.
- Reminisce with them about their child. Listen while they share their memories
- Acknowledge they are hurting. Support them but know you can't make them go through it any faster
- Offer to help care for any other children
- Provide resources for support and information
- Offer to attend a support group with them or drive to/from
- Offer to help tend to the cemetery plot or pick out special remembrance or memorial gifts

Ideas for memorial keepsakes

- Garden stones
- Wind chimes
- A plant/dish garden
- A frame with a photo of their child and their name
- A scrapbook or photo book of they and their child
- Jewelry - mother's bracelets/necklaces, angel pins
- Willow tree angels or similar keepsakes
- Ornaments with their child's name
- Memorial candles
- Name a star after their child
- Have a flag flown over the U.S. Capitol and sent to them – contact your state representative in congress

Some of my favorites

- A pin made from a drawing of the child's
- A quilt made from the child's clothes/blankets (get permission first)
- Masses in her honor
- A glass plate made with her hand and footprints
- Hand made bracelet with her name and meaningful beads/charms
- Trinkets that just showed up at her "Special place" at the cemetery
- Wind chimes and sun catchers
- Poems
- Prayer shawls
- Donations to a meaningful charity
- Plants for her memorial garden or for the home/cemetery

The best gifts of all

- Say their name
- Acknowledge their loss, their pain, and the fact that they think of their child and miss them every single day
- Say their name
- Reach out to them on the anniversary, their birth day, their death day, Mother's Day, THEIR birthday, holidays, the would be first day of school, their due date, and let them know you remember their child and how difficult these days are for them
- Send a random card or flowers
- Say their name. Share a memory. Anytime!

Please say my child's name
I am thankful when you do
and if you see a tear fall from my eye
it's my heart thanking you . . .

- author unknown



**The
Compassionate
Friends**
Supporting Family After a Child Dies

National and Internationally Recognized Events and Acknowledgment of parental bereavement

- Pregnancy and Infant Loss awareness Day/Month (October)
- Compassionate Friends Worldwide Candle Lighting – second Sunday in December at 7 pm
- National Children's Grief Awareness Day – November 17th
- Bereaved Parent's Awareness Month – July
- Bereaved sibling awareness month – November
- International Bereaved Mother's Day – May 1st
- The Christmas Box Angel of Hope Memorial Celebration – December 6th 7pm annually
 - Blackstone Valley Angel of Hope Uxbridge
 - Sturbridge- St. Anne Shrine
 - Easthampton – John Bator Park
 - North Adams – Southview Cemetery

What to say to a bereaved parent

- I'm so sorry
- I'm sad for you and the loss of _____ (their name)
- Share a memory of something you loved about their child
- Say their child's name, or ask what it is if you don't know
- What happened?
- How old were they?
- I can't imagine how incredibly painful (or devastating or hard or heartbreaking or impossible) this is for you.
- I know this must be so very hard for you.
- What can I do for you?
- I'm here for you. Anytime, anywhere. Call, text, email.
- Tell me how you are feeling today.

Things to say to a bereaved parent

- I have time. Is there anything you want to share or talk about? Tell me anything. As much as you want. No judgment. I'm here for you.
- Tell me about _____.
- How are you doing managing all of this?
- I've been thinking about you. Is there anything I can do?
- I love you.
- I don't know what to do or say, and I'm so sorry for your loss.
- I'm sending love and wishes for healing your way.
- I'm praying for you and your family.
- I can't imagine how you feel.. When I lost (a close loved one), I remember I felt _____,. Is it similar for you?
- I'm heading to the store, is there anything I can pick up for you?

What NOT to say to a bereaved parent

- You can always have more children
- At least you have your other children
- You could always adopt
- You're still young, you have your whole life ahead of you...
- Now you'll have your own angel in Heaven
- This was God's will
- God needed another angel
- Don't be angry with God (higher power you believe in)
- They are in a better place
- It's for the best
- I know how you must feel (unless you have walked in their shoes)
- I understand (unless you have also lost a child of similar age and circumstance)
- Things are better off now

Before you tell a
grieving parent to be
grateful for the
children they have,
think about which one
of yours that you
could live without.



What not to say...

- It's probably best that you forget about this/them if it hurts so much
- You didn't even get to know them
- You'll be fine (in a few days, weeks...)
- You'll get over it. Why aren't you over it yet?
- It will get better
- It's been _____ (amount of time), don't you think you should move on?
- Why do you talk about it if it makes you so sad?
- Why haven't you put away their things yet?
- You need to put this behind you and get on with your life.
- You shouldn't blame yourself. It's not your fault.
- There's nothing you could have done.
- You shouldn't feel that way.
- Their suffering is over. You should be glad for that and move on with your life
- You'll see them again someday (when you die, if you believe in that)
- They are with _____ (another deceased loved one). They are safe.
- Why do you do this to yourself?

I will stop talking about
my child in Heaven
when you stop talking
about your child on
Earth.



somee cards
user card

Supporting the bereaved lasts a lifetime

- Ways to stay connected to their child
 - Write to them
 - Journal
 - Be creative in memorializing them
 - Make a perspective list
 - Think about how to incorporate their memory into your life and important holidays/events
 - Create rituals of remembrance that are significant

Creative memories



How to support and nurture yourself, as a care provider

- Talk with colleagues, friends and family (protecting the families' identity of course)
- Professional “Debriefing” or case review – validation and learning opportunity
- Seek professional support or counseling or support of a clergy member
- Know that anger, guilt, and frustration are normal emotions – process them with a colleague, counselor, or friend
- Attend a support group or start one!
- Be aware of stress reactions, especially if prolonged or interfere with day to day function
- Journal

Taking care of you

- Body work, Reiki, Yoga, dance, meditation
- Try a virtual dream experience for yourself – to reframe the situation and heal using certain concepts (for example create a story using these elements: the day of your death, someone who has already died, your conversation with that person, a mountain, a talking bird, and a sunrise)
- Self-nurture
- The empty chair exercise – a dialogue with the deceased child where you imagine what they would say

Grief Keeping

- Often done on social media
- Maintains a connection and ongoing relationship with the deceased child
- Honors the memory of their child. Their life. Their death. Their existence. Their importance in their life.
- Provides an opportunity for others to engage in conversation about their child, to see and say their name
- Provides an opportunity for support during the difficult days
- May provide an opportunity for education and awareness, especially in the case of a rare disease or condition or an accidental death

“Death ends a life, not a
relationship”

~Jack Lemmon

“If there ever comes a day when we
can't be together, keep me in your
heart, I'll stay there forever.”

- Winnie the Pooh



Ways to honor life and death

- Create an altar or memorial sacred space with the child's photograph, a keepsake, their name creatively displayed
- Wear memorial jewelry
- Create a memorial garden
- Plant a tree in their memory
- Do something to honor them. Random act of kindness or silliness on the anniversary of their birth/death day(s).
- Say a prayer or reflect on the impact the child's life/death has had on you
- Light a candle on their anniversary or birth day in honor of their light and love

A place of honor



The Power of Social Media

- Many people use social media to express their grief or for grief keeping
- While this can bring positive support and allow those who are not comfortable with face to face support “be there” for the bereaved, it also opens the door for negative or unintentionally hurtful comments, especially on public blogs and when posts are shared
 - Blogs
 - Facebook
 - Twitter
 - Instagram
 - YouTube

It's a journey

- Coping with the difficult days
 - Birthdays
 - Holidays
 - Mother's and Father's day
 - Anniversaries (death day, due date, conception date, the date they learned they were pregnant...)
 - The firsts that will never happen for that child
 - First day of school
 - Religious rites of passage
 - Cultural rites of passage
 - Graduation
 - Weddings
 - Birthday parties for the children of friends/family or siblings of the deceased child

The gifts of grief

- Opportunity for growth and change
- Relationship changes
- The gift of life (through organ donation)
- Perspective
- Courage
- A desire to plan for your own mortality
- Resilience
- An awareness of the amazing, selfless, heart-centered work of so many professionals out there who support the bereaved every day
- Gratitude
- Release of fear
- Lead you to a new life purpose

Signs?



Life after death?

“Contacting departed loved ones is not only a deep-seated human desire, but ... also a fundamental part of the grieving process.” ~ Raymond Moody

“Acceptance”

With time, we learn to weave the life and death of our child into the fabric of our lives with the love we have for them. Everything about them permeates every fiber of our being. They become part of us, live on through us, in our stories, by saying their name, in memories, through rituals of remembrance and by celebrating their importance in our lives.

There will always be good days and bad days. We will eventually find a “new normal”, but we will never, ever be the same person we were before our child died.

Resources

- For a complete list, please visit:
outofthedarknessgriefsupport.com
 - General Resources for coping with grief and loss
 - Resources specifically for parents who have lost a child and for those with pregnancy or infant loss
 - Support groups
 - Resources for grandparents and siblings
 - Resources for professionals and caregivers
 - Resources for funeral planning
 - Places and ways to honor the memory of a child
 - Recommended reading for adults and children
 - How to create a memorial website
 - Addiction support/resources
 - Memorial gift ideas

A few of my favorite resources

- The Compassionate Friends
 - www.compassionatefriends.org
- Centering Corporation
 - www.centering.org
- SHARE Pregnancy and Infant loss support
 - www.nationalshare.org
- Bereaved Parents of the USA
 - www.bereavedparentsusa.org
- The MISS Foundation
 - www.missfoundation.org
- Empty Arms
 - www.emptyarmsbereavement.org
- Open to Hope
 - <http://www.opentohope.com/>
- The Stillbirth Alliance
 - www.stillbirthalliance.org

Remembering our babies

It's all about love



We Light These Five Candles

We light these five candles in honor of you, our loved ones who have moved on to the next place. For we know you are celebrating with us today in spirit, shining your love and light upon us.

The first candle represents our grief. The pain of losing you is intense. It reminds us of the depth of our love for you.

The second candle represents our courage - to confront our sorrow, to comfort each other, and to change our lives for the greater good.

The third candle we light in memory of you - the times we laughed, the times we cried, the times we were angry with each other, the silly things you did, and the caring and joy you gave us.

The fourth candle is the light of love. Every day we cherish the special place in our hearts that will always be reserved for you. We thank you for the gift your living brought to each of us.

The fifth candle is the light of hope. It reminds us of love and memories of you that are ours forever. May the glow of the flame be our source of hopefulness now and forever.

We love you!

We Remember Them

In the rising of the sun and its going down

We remember them

In the blowing of the wind and in the chill of winter

We remember them

In the opening of the buds and in the rebirth of spring

We remember them

In the blueness of the skies and in the warmth of summer

We remember them

In the rustling of the leaves and in the beauty of autumn

We remember them

In the beginning of the year and when it ends

We remember them

When we are weary and in need of strength

We remember them

When we are lost and sick of heart

We Remember them

When we have joys and special celebrations we yearn to share

We remember them

So long as we live, they too shall live, for they are part of us

We Remember them

Thank you!



With gratitude and wishes for peace, today and always
Namaste

Book Signing!

- Please stop by my table for Meghan's Hope and Out of the Darkness to pick up important safety information for the families you work with.
 - Every 24 minutes a child is injured in a furniture or TV tip-over accident.
 - \$5 and 15 minutes would have saved Meggie's life
 - Anchor it and protect a child today!
 - www.meghanshope.org
- If you would like to purchase a book, I am signing/dedicating them at my table at all the breaks today.
\$20

Questions?

