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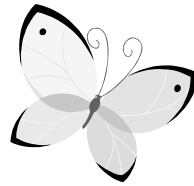
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DISCLAIMER

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We thank those bereaved parents who have shared their innermost thoughts and feelings about their precious babies in order to help others. We honor you. Your babies are always remembered.

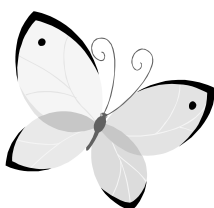
We have collected various writings over the years and have credited the author when this information is known. If we have inadvertently used a material that should be credited to a group or individual, please know that this was not done with intention and if you contact us, we will correct the oversight.

Healing Hearts Resource Guide

The unthinkable has happened to you. Your precious baby has died. This is a devastating tragedy for parents, family members and friends. This grief is overwhelming to you and this resource book is written to help guide you through the process of planning your baby's funeral, offer bereavement support and information and connect you to Cribs for Kids, a nonprofit agency dedicated to helping families through this difficult time.

Whether your baby died before birth, or you suffered a miscarriage, or your infant died of Sudden Infant Death Syndrome or a sleep-related death, we are here for you.

Please read through the information and join our parent bereavement forum at www.cribsforkids.org for online support, or call (412) 322-5680 for support.



Welcome

My heart is with you. We are truly sorry for the heartbreaking loss of your baby or babies. Cribs for Kids® offers you the comfort of this Healing Hearts Resource Book. This book has been compiled from many sources and bereaved parents have offered their thoughts, feelings, and ideas to share with you to let you know that you are not alone in your grief. There are others who truly understand and care.

This book contains advice, thoughts, feelings, hopes, and wishes from bereaved parents regarding what they did or wished they had done to make lifelong memories and have special time with their loved and lost baby or babies.

Please take some quiet moments to contemplate and discuss some of the advice in this book to see if any of these ideas resonate with you. This is the most difficult loss—your hopes and dreams for your child have been dashed and it may seem that there is no one to turn to. Please remember that we are here for you. Refer to this book as you work through your journey of grief...there is no time limit on your feelings or emotions. It's okay to feel the way that you do.

With Deepest Sympathies,

Andrea Wilson, MSW

Support and Education and Education Coordinator

Cribs for Kids®

Types of Loss

By Permission of The Teddy Love Club™ Pregnancy and
Infant Loss Support, Australia

“When I lost my baby at 9 weeks, I was devastated, so many hopes and dreams. From the time I found out I was pregnant I was already counting down the weeks and getting things organized.”

Anonymous

Miscarriage

You may find that not all of the information below is relevant to your individual situation.

Miscarriage Facts:

Miscarriage is defined as a baby/babies who dies before 20 weeks gestation and/or less than 400 grams in birth weight.

Definition:

Early miscarriage (1st trimester) less than 12 weeks.

Late miscarriage (2nd trimester) over 12 weeks.

Sometimes when women suffer a miscarriage, others around them do not understand that you have loved and wanted your baby right from the beginning. You have had such high hopes and expectations for your new baby. The amount of time your baby has been within you growing is not a measure to your heartache.

Unfortunately, the number of women who lose their baby as a result of a miscarriage is high. It is for this reason that miscarriage can be such a silent grief. Please know you are not alone. It does not matter when you have miscarried your much longed for baby, it matters that you have lost your baby and all of the hopes and dreams that came with your pregnancy.

We are here to support you.

Parents have found the information below very helpful specifically when suffering a miscarriage:

- Ask for an honest explanation of what to expect with the medical procedure or delivery of your baby.
- Seek medical attention immediately if you have miscarried at home.
- Take your time in deciding when the procedure will take place.
- As what your baby/babies may look like.
- Ask for an ultra sound pictures you may have had taken of your baby.
- Ask that the birth certificate regulations regarding your baby's birth is explained to you.
- Ask if the sex of your baby can be determined by further testing.

Some things to ask yourself:

- Do I want to name my baby/babies?
- Do I want to see my baby? Choosing to see your baby or not is a very personal choice. Do what is best for you.
- Do I want to hold my baby? Choosing to hold your baby or not is a very personal choice. Do what is best for you.
- Do I want to have a funeral/memorial service for my baby/babies?

In the following sections, there are very useful and helpful lists of information about delivering your baby, spending time with your baby, creating memories with your baby and some things you may expect.

Termination of Pregnancy for Fetal Abnormality

You may find that not all of the information below is relevant to your individual situation.

Some parents will be faced with the hardest decision they will ever have to make, after an ultrasound or test shows a serious problem with their baby, or shows that the mother is too unwell to carry the

baby to term. In some situations, the baby has little or no chance of surviving birth, the baby may be diagnosed as not compatible with life, or if they survive, they will have very poor quality of life. The parents of these babies must make the decision to continue with their pregnancy and let nature take its course until the baby passes away or to end their pregnancy.

The decision to end the pregnancy is heartbreaking. Many people cannot understand that parents who choose to end their pregnancy do it out of love for their child, and often make the mistake of saying that the parents could not have loved their baby if they chose to let their baby go. Whatever decision is reached, it is made with love for the baby and it is the right decision for the parents, the baby and the immediate family.

Parents have found the information below very helpful specifically when experiencing a termination of pregnancy for fetal abnormality:

- Do not be afraid to ask for a second opinion—it is your baby and your need to know everything you can to make the right choice for you and your family.
- Ask if there are any fetal abnormality support groups or resources etc.
- Please don't be pressured into any decision regarding the outcome of your pregnancy, this is a very individual decision.
- Ask for an honest explanation of what to expect with the medical procedure or delivery of your baby.
- As what your baby may look like.
- Talk to someone you trust if you are feeling pressured.
- Take your time making your decision on what you would like to do. It is a difficult decision and you need to ensure it is what is best for you, your baby and your family.
- Know that you may, if you choose to, hold a funeral, burial or cremation service for your baby.
- Ask that the birth certificate regulations regarding your baby's birth be explained to you.

“Many people often refer to genetic inducement of labour as a ‘choice’; I have never felt this way. My son’s condition was not compatible with life. I had no choice in that. The only choice I did have was to have my son’s birth induced or to wait until he died in utero. For me personally I knew I couldn’t have coped with that.”

Jaylee in Memory of ~Kai~

- Most importantly, do not feel guilty for making the choice to induce your labor/terminate your pregnancy. You love your baby and you have made this decision that is right for you and your family.

If the birth of your baby has been induced, here are some questions to ask yourself:

- Please do not be pressured into any decision about the delivery of your baby. Do what feels right for you; this is a very individual decision.
- Do I want to see my baby? Choosing to see your baby or not is a very personal choice.
- Do I want to hold my baby?
- Do I want to name my baby?
- Do I want to spend time with my baby?
- Do I want my family and friends to meet my baby?
- Do I want to have a funeral/memorial service for my baby?

Stillbirth

“To have to experience the birth of your baby so silent, so still. Not to hear that beautiful cry echoing the room, leaves such an unforgettable impact on your whole life.”

Trudi in Memory of ~Amie-Lee and Emily~

You may find that not all of the information below is relevant to your individual situation.

Stillbirth Facts

Stillbirth is defined as a baby/babies who pass away after 20 weeks gestation (or who weigh more than 400 grams), or babies who are not born alive.

Sometimes women are told during an ultrasound whether it be routine or because the mother is concerned over her baby's movements, 'Sorry, we cannot find a heartbeat'. It is so very hard to take in those words and accept them while, then, having to make decisions about delivering your baby.

Parents have found the information below very helpful specifically when suffering the stillbirth of their baby:

- You may be advised to go home and then come back at a later time/day to deliver your baby. This may seem ridiculous but it does actually give you time to think and make decisions. You may want to bring something special from home for your baby or get the camera. It gives you time to consider what type of delivery is best for you and your baby.
- Please don't be pressured into either decision about the type of delivery of your baby. Do what feels right for you, as this is a very individual choice.
- Ask for an honest explanation of what to expect with the delivery of your baby.
- Ask what your baby may look like.
- Ask that the birth certificate regulations regarding your baby's birth be explained to you.

Some things to ask yourself:

- Do I want to see my baby? Choosing to see your baby or not is a very personal choice. Do what is right for you.
- Do I want to hold my baby? Choosing to hold your baby or not is a very personal choice. Do what is right for you.
- Do I want to name my baby?
- Do I want to spend time with my baby?
- Do I want my family and friends to meet my baby?
- Do I want to have a funeral/memorial service for my baby?

Neonatal Death

“Sometimes all of our best expectations are turned upside down and what we thought was going to be a wonderful thing, turns out to be something entirely different.”

Lisa in Memory of ~Sophie~

You may find that not all of the information below is relevant to your individual situation.

Neonatal Death Facts

Neonatal Death is defined as babies that are born alive at any gestation and then dies at any time within 28 days of life.

Neonatal death can happen in many different ways for babies and their parents:

- Babies can have a pre-diagnosed terminal condition.
- Babies can be born early (often too early/before a viable gestation) and fight for life but pass away within hours/days/weeks of being born.
- Babies can be born and everything seems perfect then an illness or condition is diagnosed.
- Sometimes a perfect pregnancy can turn tragically for the worst during childbirth.

Here we have some shared feelings and experiences from other parents who have experienced the neonatal death of their baby:

- Ask for a second opinion.
- Know that you can change/request specific medical staff or hospital.
- Be pro-active and have control over your baby's care.
- Take many photos/videos of your baby, even with the tubes and machines in the way.
- Ask whether palliative care at home is an option.
- Learn as much as possible about your baby's condition/diagnosis.

- Ask that the birth/death certificate regulations regarding your baby birth/death is explained to you.
- Continue to write down questions as you think of them, as in most cases there will be a follow up appointment to discuss your baby passing and this can be a very confronting and emotional time, so having the questions already written down can help with this.
- It may also help to take someone with you who can also listen and take down notes to follow up on at a later stage if required.

Babies Who Are Fighting for Their Lives in the NICU

“In our case, the [pediatrician] that treated Nicholas was the person who we felt most comfortable with—with this in mind we requested that all autopsy results went to him (we asked him if we could) so that this could be discussed with him and not someone that we didn’t feel comfortable with.”

Nichole in Memory of ~Nicholas~

Ask for photographs or video footage to be taken of your baby throughout their stay in the NICU. Sometimes parents are waiting for the tubes to be removed and the baby to have graduated to the next step. The photos and video footage of them while alive will always be treasured memories:

- Talk with the other families that also have babies in the NICU. Support is incredibly important through this time. Knowing you have someone that can listen and understand may help you get through each day.
- Learn as much as possible about your baby’s condition.
- Write down any questions you have.
- Talk to the medical staff about the different types of machines that may be helping your baby to survive. Understanding what they do and the sounds they make will give you a better understanding of your baby’s care.

- Ask whether palliative care at home is an option for a terminally ill baby.

In the following sections, there are very useful and helpful lists of information about delivering your baby, spending time with your baby, creating memories with your baby and some things you may expect.

Multiple Birth/Pregnancy: Loss of One

You may find that not all of the information below is relevant to your individual situation.

For mothers who have suffered the loss of one of their babies early in a multiple birth pregnancy, sometimes they have to carry both babies longer to give the survivor the best chance at life. Often people forget that the mother has suffered a loss too and focus all of the attention on the surviving baby. There have been many expectations for a 'going longer mom' to 'just be so happy she has one baby alive'. Her heart is torn.

Parents have found the information below very helpful specifically when suffering the loss of one of their multiple birth babies:

- Please don't be pressured into either decision about delivery of your babies. Do what feels right for you, this is a very individual choice.
- Ask for an honest explanation of what to expect with the delivery of your babies.
- Ask what your baby may look like.

There is an important factor for the baby who has passed. He or she may have passed away weeks, even months, before delivery. It may not be recommended you see your baby. Please remember this is a very personal choice. Your baby may be compressed and macerated from the amount of time in utero, however some families have told how their baby is and was perfectly formed and thus preserved this way.

Some things to ask yourself:

- Do I want to name my baby who has died?
- Do I want to see my baby alone and/or with his or her survivor?
- Choosing to see or hold your baby or not is a very personal choice
- Do I want to hold my baby who has died along and/or with his or her survivor? Choosing to see or hold your baby or not is a very personal choice.
- Do I want to have photographs taken of my baby who has died with my surviving baby together? This in time may become a treasured possession for the surviving child also.
- Do I want to hold a funeral/memorial service for my baby.

Multiple Birth/Pregnancy: Loss of Both or All Babies

“I was so excited and thrilled to find out we were expecting twins! So special! When I found out both of my little girls hearts had stopped beating, I just couldn’t believe it. Both of them?? Almost like, I have two babies how could I lose both of them? (Not that I ever would have wanted only one of them ever.) I really clung to the hope that it was all so wrong. But it wasn’t. There had been so much excitement over having double the delight expecting twins. But for me it felt like a double blow, a double loss.

Trudi in Memory of ~Amie-Lee and Emily~

You may find that not all of the information below is relevant to your individual situation.

When you have lost both of all of your babies from a multiple birth pregnancy the feelings and making of precious memories is much the same as having lost one baby but for both or all of the babies. It is heart breaking to not take any of your babies home.

Parents have found the information below very helpful specifically when suffering the loss of all of their multiple birth babies:

- You may be advised to go home and then come back at a later time/day to deliver your babies. This may seem ridiculous but it does actually give you time to think and make decisions. You may want to bring something special from home for your babies or get the camera. It gives you time to consider what type of delivery is best for you and your babies.
- Please don't be pressured into either decision about delivery of your babies. Do what feels right for you. This is a very individual choice.
- Ask for an honest explanation of what to expect with the delivery of your babies.
- Ask what your babies may look like.
- Make the precious memories with your babies together and apart. Together as Twins, Triplets, Quads and as individual little people, too.
- Parents of twins have often spoken of how they wished they had a photograph of them holding their babies in each arm, (something they had imagined and dreamed of throughout their pregnancy).
- Ask that the birth certificate regulations regarding your babies' birth is explained to you.

Some things to ask yourself:

- Do I want to name my babies?
- Do I want to see my babies? Choosing to see your babies or not is a very personal choice. Do what feels right to you.
- Do I want to hold my babies? Choosing to hold your babies or not is a very personal choice. Do what feels right to you.
- Do I want siblings/other family members/friends to meet my babies?
- Do I want to have a funeral/memorial service for my babies?

In the following sections, there are very useful and helpful lists of information about delivering all of your babies, spending time with

all of your babies, creating memories with all of your babies and some things you may expect.

Sudden Unexpected Infant Death (SUID)

SUID is the umbrella term that encompasses any sudden, unexpected death of an infant that occurs during infancy. When this occurs, a thorough post-mortem investigation must be done to determine the cause of death, including an autopsy, review of the baby's history and an investigation of the death scene. After the case investigation, SUIDs may be attributed to many different causes of death, such as suffocation, asphyxia, entrapment, infection, ingestions, metabolic diseases, arrhythmias and trauma.

Sudden Infant Death Syndrome (SIDS)

If, after the complete investigation, all evidence is negative and no cause of death can be determined, only then can the death be diagnosed as Sudden Infant Death Syndrome because this meets the criteria for SIDS: the death cannot be explained after a thorough case investigation, including a scene investigation, autopsy, and review of the clinical history. (Willinger, 1991). Approximately 80% of SUID deaths are diagnosed as Sudden Infant Death Syndrome after investigation with the remaining 20% having a clear cause of death.

It is difficult for a medical examiner or coroner to distinguish between a SIDS death and a sleep-related infant death because the risk factors for SIDS mirror the risk factors for an accidental infant death, and an accidental suffocation death cannot be determined by autopsy alone. The death scene is vitally important to the investigation of the infant's death.

Sudden Infant Death Syndrome is thought to be the end result of a complex interaction of multiple factors. According to the Triple Risk Hypothesis (Filiano, Kinney, 1994), SIDS occurs when three factors are present:

- I. an underlying vulnerability in the infant,

2. a critical developmental period (peak time 2-4 months of age)
3. Outside stressors (prone/side sleep position, exposure to nicotine/smoke, overheating, bedsharing, head covering, soft bedding.)

The risk factors for SIDS and sleep-related infant deaths overlap and reduce both of these causes of death.

Accidental Sleep-Related Infant Deaths

Sometimes an infant dies of overlay or suffocation while sleeping in an adult bed with parents or on a sofa. The autopsy reveals suffocation or asphyxia as the cause of death. The fact that this death could be prevented is the cause of terrible suffering for the parent or caregiver. There are some things to consider.

1. No parent(s) can be constantly vigilant over their child 24 hours a day, 7 days a week. It is impossible. Sometimes our guard is down or a miscalculation is made and an infant dies accidentally.
2. What was the intent of the parent? To do harm? Of course not. However, this type of death requires extra understanding and sensitivity. "Honor the mission, challenge the methods."
3. Since parents bear the responsibility for their child, they may see the death of their child as an ultimate failure in their parental roles.
4. Help parents to understand that sometimes in spite of all of our best intentions, tragedy occurs. Help parents to internalize that "they did the best that they could at the time."
5. Guilt is a normal feeling that all bereaved parents feel to some extent after the death of their child.
6. Help parents focus on the positive, loving things that they did with their child.

Preparing for the Birth of Your Baby

Your Hospital Stay

“No matter what age you are it still happens, I found that when I lost Kloe. I was thinking to myself, ‘but I’m only 21. Why has it happened to me?’

Stacey in Memory of ~Kloe~

“The night before I went into the hospital was a complete blur, I don’t think I slept. I was scared of going through labour and giving birth to my baby that was not alive but I was also excited that I would get to meet my son. I just clearly remember I was full of so many mixed emotions.”

Jaylee in Memory of ~Kai~

Finding out that your baby has passed away or knowing your labor is going to be induced is truly devastating. You may be feeling many mixed emotions and wondering what will happen next.

The birth of your baby is meant to be a wonderful and blissful time. For many the thought of birthing their baby that has passed away or knowing their baby will be stillborn is very overwhelming.

Some things to consider and ask:

- Will I have a private room?
- Will I be away from new mothers and babies?
- How long can I stay?
- Can my baby stay in my room?
- Can my partner stay overnight?
- Visiting hours?

What to Bring from Home

Some families have told us how this was the last thing on their mind when they had just found out such devastating news about their baby or babies.

Here is a simple list of some things you may want and need to bring from home:

- Clothes/toiletries for Mom
- Clothes/toiletries for Dad
- A comfortable pillow
- Your birth plan
- Medical/maternity notes
- Camera/Video camera
- Music
- Massage oil
- A journal/diary/paper to write down your thoughts
- Your cell phone/address book
- A special blanket for baby
- Special clothes/outfit for baby (most hospital do have clothes made just for babies)

Preparing for the Birth

“There were things I didn’t do that I wish I had, and choices I made that I would have made differently, simply because I was rushing myself.”

Casey in Memory of her Baby

The following are some gentle ideas and suggestions of what other bereaved parents have found helpful to know in their time of preparing for the birth of their precious baby.

Is there is something that you want to ask but you doubt yourself? Please remember to follow through with what you are thinking. Do ask, as it is okay to ask for anything.

Questions and things to consider:

- Write down any questions you may have.
- Ask any questions that you may have.
- Ask as many questions as you feel you need to know.
- Please don't be pressured into either decision about delivery of your baby. Do what feels right for you. This is a very individual choice.
- Ask for an honest explanation of what to expect with the delivery of your baby.
- Ask what your baby may look like.
- Ask what size your baby might be.
- Ask that the birth certificate regulations regarding your baby/baby's birth is explained to you.
- Ask what the procedure is for funeral arrangements.
- Know that you may if you want to hold a funeral/burial or cremation service for your baby.
- Think about anything you may like to do with your baby.
- Think about anything you would like to bring from home for your baby such as a blanket, shawl or little hat.
- What mementoes can I have from my baby's birth? (You may like to organize a professional photographer and/or arrange hand and foot casts.)

Some things to ask yourself...Do I want to...:

- Take some last photos of my pregnant belly?
- Name my baby?
- See and or hold my baby? Choosing to see or hold your baby or not is a very personal choice. Do what feels right to you.
- Hold a funeral/memorial service for my baby?
- Have photos taken of my baby and of myself/partner with baby?
- Have video footage taken of my baby and of myself or family with baby?
- Allow other family members to see my baby?
- Put a birth and/or death notice in the paper?

Shared suggestions that were helpful to other parents' experiences:

- Offered a private/single room (which is away from the nursery and new mothers and babies.)
- Encouragement but not pressure to hold and or see your baby. To have as much time as you want with your baby.
- To be given as many choices and possibilities to make precious memories with your baby/babies.
- That you are shown consideration and compassion.
- That you know you can ask for different particular staff.
- That repertoire with your midwife is important. That you are given honest, full and clear explanations of what has happened to your baby and what will happen next.
- That you are given choices and offered suggestions.
- That you are offered to see a counselor, social worker and/or hospital chaplain.
- That you are offered as much information and literature of bereavement support resources available.
- That you are not pressured into filling in paperwork until you feel you are ready.
- That the process of making funeral arrangements is explained to you.
- The birth certificate regulations regarding your baby's birth is explained to you.
- That you are not pressured into leaving the hospital too early.
- If you want pictures or other mementoes (like the blanket your baby was wrapped in) don't hesitate to ask.
- Many hospitals keep the photos in your baby's file until you request them.
- If there is something you want to do for your baby while in the hospital, ask to do it. It is all right to ask and it is very normal to want to do these things with your baby.

What My Baby May Look Like

“I was scared and worried of what to expect my girls to look like. They were so much more perfect and beautiful than I could have ever have imagined. They didn’t seem as tiny once snuggled in my arms. They both had the most gorgeous cherry red lips.”

Trudi in Memory of ~Amie-Lee and Emily~

“I wanted so much to run my fingers over every inch of his body, but his skin was so macerated. I couldn’t bear the thought of causing any more damage to his beautiful, tiny body.”

Melissa in Memory of ~Mitchell~

Many bereaved parents have wanted to know what to expect with the early arrival of their baby or what their baby may look like.

Here are some shared experiences from other bereaved parents.

You may find that not all of the information below is relevant to your individual situation:

- ‘Our baby looked so perfectly formed -- just tiny.’
- ‘She had exquisite details.’
- ‘Her little mouth flopped open and that was the only thing that made her not look alive.’
- ‘He was soft and his skin was delicate but he was oh so perfect.’
- ‘They really just looked like they were sleeping.’
- ‘They weren’t even as tiny as I had imagined.’
- ‘They had gorgeous cherry red lips. It looked like they had lipstick on.’
- ‘I never expected his delicate skin to be peeling. I had no idea this happened.’
- ‘His little body could fit into my husband’s hand.’

Your Care and Treatment in the Hospital

“If you don’t ask, you don’t get and no question or request is silly or ridiculous at all.” *Diane in Memory of ~Emily~*

It is hoped that all bereaved parents are treated with the best care and regard and are offered the many choices available. We hope the things listed are offered or done for you and you will not need to ask for them yourself:

- A private/single room (which is away from the nursery and new mothers and babies).
- Encouragement, but not pressure, to hold and/or see your baby.
- To have as much time as you want with your baby.
- To be given as many choices and possibilities to make precious memories with your baby.
- That any reasonable request you do have is not refused. That you are shown consideration and compassion.
- That you know you can ask for different or particular staff.
- That you are given honest, full and clear explanations of what has happened to your baby and what will happen next.
- That you are given choices and offered suggestions.
- That you are offered to see a counselor, social worker and/or hospital chaplain.
- That you are given as much information and literature of bereavement support resources available.
- That you are not pressured into filling in paperwork until you feel you are ready.
- That the process of making funeral arrangements is explained to you.
- The birth certificate regulations regarding your baby’s birth are explained to you.
- That you are not pressured into leaving the hospital too early.
- If you want pictures or other mementoes, like the blanket your baby was wrapped in. Don’t hesitate to ask. Many hospitals will keep the photos in your baby’s file until you request them.

- If there is something you want to do for your baby while in the hospital ask to do it. It is all right to ask and it is very normal to want to do these things with your baby.

The Birth

“Any physical pain from a c-section does not even rate to the heartache of losing my girls. I knew a c-section was right for me—for us. I do not have any regret whatsoever of choosing to deliver my girls that way. They came from me, I delivered them. I gave birth to them. It is not about how they were born—they were still born that is what matters.’

Trudi in Memory of ~Amie-Lee and Emily~

Please don't be pressured into either decision about delivery of your baby. Do what feels right for you, as this is a very individual choice. There is no right or wrong way. The type of delivery will depend on your medical circumstances and the timing of your delivery.

Types of birth:

- D & C procedure
- Surgical termination
- Induced labor
- Natural labor
- Caesarian section
- Birth of baby at home



Please talk to your doctor or midwife about pain relief options.

After the birth of your baby you are likely to receive medication to stop your milk from coming in. Please discuss this medication further with your doctor. If you are not sleeping, it is okay to ask for medication that may help this. Before and after the birth of your baby this is very important for your well-being.

“Knowing that a little girl was on the way was a dream come true. From the moment I heard at the ultrasound, “it’s a girl!” I dreamt and imagined a lifetime of experiences and memories. From her first day in Kindergarten to her Prom, and most importantly her wedding day. I awaited to hear, “I love you” from my princess.”

Dana Ann Slizik in Honor of ~Samantha Ann~

Special Time with Your Baby

“I wish very much that I followed my instincts and held Liam against my bare skin.”

Kylie in Memory of ~Liam~

You may find that not all of the information below is relevant to your individual situation.

The time you spend with your baby will become the treasured memories you keep forever. It is a very personal choice as to whether you see and hold your baby or not, there is no right or wrong way. Please do what is right for you and if you are not able to see your baby you can ask for a photograph to be taken, so that if you wish you can look at it later. We hope you create and capture the treasured memories and moments spent with your baby that feels right to you.

Suggestions for Spending Special Time with Your Baby

Holding your baby:

- It is okay just to look at your baby.
- Hold, cuddle and kiss your baby for as long as you feel you want and need to.

Time with your baby:

- Spend as much time as you feel you can and want with your baby.
- It is okay to keep on asking the hospital staff to bring your baby back to you.
- It is okay to keep your baby with you overnight.
- Read a story, sing and or tell your baby all the things you wish you would have been able to if he or she was alive.
- It is okay to take your baby outside for a walk.
- Find out if you may take your baby home just for a little while.

Bathing your baby:

- You might like to give your baby a bath.
- The hospital might have some clothes that will fit your baby or you might have something special you want to dress your baby in.
- Take photographs and/or video footage during this beautiful bath time.

Photos of your baby:

- Ask for a photo or photos of your baby to be taken by the staff. Most hospitals have a digital camera that they can do this with.
- Take your own photos or have someone take photos. You can have your photos printed in color or black and white.
- You may not feel you want to look at the photos right away but having the photos mean if you do change your mind you will have them.
- Take photos of your baby close up, of your baby wrapped in a blanket, with you holding your baby, of your baby in what they are wearing.
- Take photos of your baby with a teddy bear or other special gift.
- You may want to organize a professional photographer (see Now I Lay Me Down to Sleep).
- You may want to use your video camera. It may not be footage that you can watch at first but there may come a time when you do want to see it.
- Take photos of the flowers/cards you receive.

Writing/Journaling:

- Keep a special journal of your time in the hospital.
- Write all about your baby, your thoughts, what you are feeling or poetry.
- You could write a letter or special message to your baby.

Mementos:

- Ask for special mementos of your baby to keep, such as the tape measure used, a precious lock of hair, the crib name tag, your baby's hospital band.
- Ask for hand and footprints printed in ink.
- Ask if the hospital does hand and foot castings of your baby.
- You may want to ask for and keep the clothes that your baby was wearing and blanket he or she was wrapped in.

"I regret not having a photo taken of my girls with me. I didn't want my photo taken at the time as I was in so much emotional pain, I didn't want to have to see myself like this. Now I wish I'd had one taken."

Kathy in Memory of ~Madeline and Ashleigh~

"I always wish I had a lock of Rachel's hair—no one offered either at the hospital or the funeral home and it wasn't something I thought about at the time, but wished for later. I also wish I had a photo of Rachel at the funeral home. It might sound odd, but that was part of her being here, too."

Eileen in Memory of ~Rachel Ann~



Thoughts and Reflections

A Loving Goodbye: A Guide to Arranging Your Baby's Funeral

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The unthinkable has happened.

Your baby has died suddenly, with no warning. No one can tell you why. You're in a daze. You may be angry and confused. You can't believe it's true. You are feeling a deeper pain than you have ever known.

This information is for you and for those who will support you through these first difficult days and weeks. If it's hard to read this now, give it to a friend or family member who can help.

Over the next few days, you will be making important decisions about your baby's funeral or memorial service. This will be your special way of honoring your baby. This will be one way of giving your baby a loving good-bye.



"I felt really lonely and sick—like I wanted to die. I had this sick feeling in my stomach—a weird feeling of emptiness. I didn't know what to do without her. My arms ached to hold her."

Where Do You Begin?

You may wonder where to begin or who to ask about making funeral arrangements for your baby. Friends, family and clergy will

want to help in any way they can. Here are a few ideas to keep in mind.

- **Ask a family member or friend to help you figure out what's best for you.**

Together you can look over this booklet and talk about what you want to do. With this in mind, your friend can call several funeral homes in your area. He or she can also get in touch with the local SIDS group for support.

You may want to talk with a pastor, rabbi, priest, or other spiritual leader. Once you know what is in your area, it would be good to sit down and talk about it. It helps to have a friend say, "These are some of the things you can do. What seems best for you?"



"We sat and talked with our family before we went to the funeral parlor. We wrote down what we wanted. If it got hard, we could just give him the paper."

Take the Time You Need

Making these final decisions about your baby may take some time. Usually there is no rush. If you need more time to think, take the time.

- **Do what is right for you.**

There is no right or wrong way to have a funeral. Saying good-bye to your baby is a very personal and private thing. Ask for what you need, even if you think it won't make sense to others.

- **Choose a funeral director you feel comfortable with.**

You don't have to pick the first person you call. Find someone you feel will support your needs and choices. Ask about costs and the special things you want done.

- **Be patient with yourself and each other.**

No one can be protected from the pain of losing someone so very loved. Everyone goes through this pain in their own way and at their own pace.

“Being together made our hearts stronger for each other. We knew there wasn't anything we could have done.”

It's a good idea to choose a funeral home while your baby is at the coroner's office.

Because your baby has died suddenly, an autopsy must be done by the coroner. The autopsy will show if your baby died of Sudden Infant Death Syndrome (SIDS) or a different cause of death. The autopsy itself takes only a few hours. But there are many tests that need to be done. It may take a long time to hear for sure that it was SIDS. You may need to ask the coroner for your baby's final death certificate, later on.



In the meantime, remember:

- **You didn't do anything wrong.**

- **There was nothing you could have done.**

Your baby may have to stay at the coroner's office for several days. Then your baby can be taken to the funeral home.

Funeral Choices

Here are some of the choices you can make. In most cases, you can choose any of these. You can combine them any way you want. If there is something special you want done, ask your funeral director. He or she wants to help.

- **If you want a service, do you want:**

- a funeral service?
- a memorial service?
- a graveside service?

- **Do you want the service to be held:**

- in your home?
- at your place of worship?
- at the funeral home chapel?

- **If there is a casket, do you want it:**

- open or closed?

- **If you want a viewing, do you want it private or public?**

These choices will be described in more detail on the next pages. You don't have to find out every detail yourself. You don't have to make every decision alone.

“We had a really supportive friend who just walked us through it. She helped us with the things we wanted done but just couldn't do ourselves. And our funeral director was great. He explained our choices and said, ‘You tell us what **you** want.’ ”

Do you want cremation or burial?

This is a very personal choice. If you have strong personal or religious feelings about either choice, don't ignore those feelings.

When thinking about cremation:

If you choose cremation, you can decide what you want to do with your baby's ashes. But you don't have to decide right away. You can wait and do what is best for you.

- The ashes can be buried in a small cemetery plot or put in a cemetery niche. You will need to talk with a cemetery about this.
- You can tell your funeral director to scatter the ashes on the ocean.
- You can take the ashes home to scatter later.
- You can keep them at home.

Some parents find that they want a place to visit later on. You might want to have a park bench put in or have a tree planted in your baby's memory.



"I wish we had buried our baby's ashes. We didn't tell the funeral home where we wanted them scattered, so we never really knew. I found I needed a place to go. So we had a bench put in the cemetery in her memory."

When thinking about burial:

If you choose burial, a cemetery plot is needed. In many places, the cemetery is not a part of the funeral home. A family member or friend could make these calls, too.

You can buy a family plot or you can buy a small plot just for your baby. Some cemeteries have a special section for babies.

Some parents worry about the costs of burial, knowing that cremation costs less. If this worries you, tell your funeral director. He or she may be able to help in some way. And most cemeteries can help you make a payment plan. Family and friends may also be able to help with such expenses.

Some parents wonder about headstones. You can wait and decide about this later. When your baby is buried, a marker with your baby's name is placed on the grave. A headstone may be put on any time later. Then you will have time to think about what you want on the headstone.

"We didn't want a formal service. My wife and I took our daughter's ashes out on the ocean. As we scattered her ashes, a dolphin glided by. It felt like we were giving her back to life."

What kind of service do you want?

A funeral service is held before the burial or cremation. A memorial service is usually held afterwards. The type of service you choose depends on your family's needs and beliefs. Some families have both. Some parents prefer to have a private service as soon as possible. Others would rather wait for a while.

Where do you want the service held?

The memorial or funeral service can be held at the funeral parlor, at your own church or synagogue, at your home or at the gravesite. Some parents are comforted by being in their place of worship. Other parents would rather use the funeral home chapel. Some parents choose a garden or park. Think about the place that would be best for you.

"I wanted a burial for my baby. But I worried that I couldn't afford it. I worked it all out with the funeral home. And there was a donation box at the funeral. That really helped. "We delayed our service so out-of-town people could come. It helped to wait. We could talk with our pastor about what we wanted in the service."

Do you want an open or closed casket?

Many parents wonder about having a special viewing of the baby and about having an open or closed casket. This, again, is a personal choice.

For many people, seeing the baby seems to be a needed part of saying good-bye. This can be done in many ways. There could be:

- a public viewing for family and friends a day or so before the funeral.
- a private viewing for you and close friends and family just before the funeral.
- an open casket at the funeral.

Some parents worry about how the baby will look. They think about the autopsy or how the baby looked when he or she was found. You can't tell an autopsy has been done when the baby's clothes and hat are on. And after embalming, the baby does not look like he or she did when found.

Seeing the baby at the funeral can be a real comfort for some parents. For others, seeing and holding the baby at home or in the hospital is enough.

As always, do what is best for you.

“I was looking at her, touching her. I couldn't leave her. She looked really beautiful in the coffin. It helped people having it open. It helped them understand that nothing had been wrong with her.”

“I went back to the funeral parlor six months after her death to ask what they dressed my baby in. I didn't know I had the option to dress her at the time and I was tormented.”

“My aunt read a beautiful poem at the service. It meant so much to us.”

“I had a chance to say good-bye and hold our baby at the hospital. My husband had been out of town, so he was able to hold him and be with him at the funeral home. But we didn’t want an open casket at the funeral. That would have been too hard on us.”

Making Your Good-bye Your Own

There are so many ways you can make your baby’s funeral special. Here are some things other parents have done or wish they could have done.

- Bringing flowers from your garden.
- Arranging for a spray of flowers for your baby’s casket.
- Choosing a special outfit for your baby.
- Dressing your baby yourself or having a friend dress your baby for you.
- Tying your baby’s bonnet or putting on the shoes.
- Having pictures taken at the funeral by a friend or the funeral home.
- Keeping a lock of your baby’s hair.
- Making a footprint or handprint.
- Choosing a special verse, prayer, song, or lullaby for the service.
- Placing a toy, a blanket, or something special to you in the casket with your baby.
- Bringing your baby book or photo graphs of the baby with you to the service.

You may want to hold your baby one more time before the funeral. This might be important if you haven’t been able to hold your baby since he or she died. Ask the funeral director about this if it is important to you.

Remember, nobody has ever gone through your grief. Do what you need to do, even if others might think it strange.



“We have no pictures of him. I would have liked to have had pictures taken. Even at the funeral, that would have been good.”

“I was afraid to ask for what I wanted. I was afraid someone would think I was crazy.”

A word about tradition:

Your family's traditions may be very important to you. Tell your funeral director about them.

For example, because of your tradition, you may not want your baby's body embalmed. Embalming does not have to be done. If you do not want it to be done, tell your funeral director.

Some families may want to take the baby home for a special time of family prayer. Talk to your funeral director about how this can be

“After my baby was cremated, I put a small amount of his ashes in a special leather pouch. I wear it around my neck, next to my heart. It is to help the grieving through the rough days ahead.”

done, if it is important to you.

There may be other things important to you and your family. Talk to your funeral director about what you want.

Most of the time, your traditions can be honored.

What about our other children going to the funeral?

We would all like to protect our children from the pain of death and sorrow. But it can be good for children to go to the funeral, if they want to. The funeral gives children a way to say good-bye and show their love for their baby brother or sister. Some children feel better if they can give some small gift – a drawing, flower or small toy – to the baby.

Ask a family member or friend to be with your child and explain what is going on. Your child's questions can be answered in a simple, loving way that suits his or her age.

Going to the funeral may help your child feel more secure and part of the family. But you know your child best. Going to the funeral is one way for your child to say good-bye. There are other ways you can help your child show these feelings.

How Do We Deal With the Costs of the Funeral?

For many families, any unplanned expense presents real problems. Dealing with your baby's death is hard enough without having to cope with money worries. But there are ways to have a lovely service without spending beyond your family's means.

"We both wanted our girls to be there. They were always by his coffin during the funeral. It really helped them, I think."



- **Ask your local Health Department for advice.**

In some counties, social services have some funding to help parents with funeral costs.

- **Let your funeral director know what your situation is.**

Your funeral director can suggest ways to have a beautiful service at a low cost. Payments can often be made over time, if needed.

- **There are services the funeral home provides that your family can do instead.**

Ask your funeral director what those services are. Some may be things your family would like to do.

"Different funeral homes may have different charges for the funeral of a baby. You need to talk to more than one. It's okay to shop around. It's okay to change your mind."

Basic Steps for Getting Help

- Talk with your trusted friends, family members or clergy about what you want. You don't have to deal with every detail. Ask for help.
- Ask a friend or family member to help make the needed calls.
- Call a local bereavement group or Public Health Nursing Department for support.
- Call several funeral homes. Find out what can be done and how much it costs. If you plan to bury your baby or your baby's ashes, you may need to call cemeteries.

Your Special Ideas and Requests

Do you want cremation or burial?

What kind of service do you want?

Where and when do you want the service(s) held?

What details are important to your family?

Things to ask the funeral director (costs, special requests and so on):

“Never thought I would have to make decisions for a casket, an open/closed viewing, what my little girl would wear forever and what would be buried with her. Instead of holding my princess hours after her delivery, I was doing these things.”

Dana...in Honor of ~Samantha Ann~
Precious Daughter of Dana Ann and Rob Beloved Sister to
RJ and Daniel

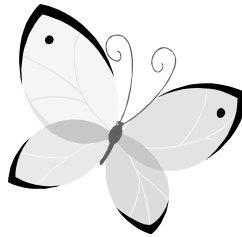


Special things to be done:

Remember, this funeral is to help **you** through the most difficult loss of your life.

- **You can do what you need to do.**
- **You can take your time.**
- **You can follow the wisdom of your tradition and heritage.**
- **You can go your own way if you need to.**

Ask friends, family, clergy, and your funeral director for help in getting what you need to make this
a loving good-bye.



The Time Ahead

Going Home

Everyone's journey is a very unique experience, one that you can work through step by step on the support that is around you.

Leaving the hospital and going back home can be very difficult and confronting, bringing many

“Her room decorated for a princess and painted in baby girl pink. Her detail, every piece of clothing anxiously and happily awaited her arrival.”

*Dana Slizik for ~Samantha Ann Thompson Slizik~
Precious Daughter of Dana Ann and Rob Beloved
Sister to RJ and Daniel*

emotions to the surface. Actually walking out of the hospital with such empty arms can be the most difficult thing in the world. Many people tell of going home, even with family, friends and loved ones with them but still feeling very alone and lost. Facing the reality of all the broken plans, hopes and dreams of your baby coming home with you can be heart wrenching.

Know that these feelings are very normal. You might find it helpful to talk to someone, tell someone how you are feeling, write down your feelings, join a support group, maybe an online support group, so you can share and express yourself right when you are feeling sad and the need to talk. Some parents have found writing or journaling your personal thoughts and feelings to be very helpful.

Nursery and Your Baby's Belongings

You may have a nursery or special room set up for your baby. A room that you would have put a lot of thought and love into setting up. The room may feel so empty and be quite hard to go into or walk past. It is okay to shut the door and return when you feel you are ready.

The baby's room may also bring you some comfort and you might find yourself feeling quite close to your baby in that room. It is a normal reaction to feel this way, if you are having a hard time with making decisions about what you are going to do with your baby's things and your baby's room please reach out and talk to someone close to you about your thoughts and feelings.

Here is a list of other families shared thoughts, feelings and ideas.

- You do not have to pack up your baby's nursery or belongings.
- If you do want to, you might want to do it alone or you could ask your partner, friend or relative to help you.
- You might like to only pack up a few things.
- You might like to keep some things.
- No one should pack up your baby's belongings or nursery unless you ask or tell them you would like them to.
- Are there some items you want to take back to the place of purchase?
- If you do want to, you might want to do this yourself or ask someone to do it for you.
- Even in the time ahead you may still like to keep your baby's things, you do not have to pack them away.
- Do what feels right for you.

"I held onto many of Samantha Ann's things for a long time. I felt letting go of them was letting go of her. I recently gave them to a close friend having a girl. Seeing her things worn by a new life makes me feel that both Samantha Ann would be proud as well as I. I kept a few things."

In Memory of Samantha Ann Thompson Slizik
Precious daughter of Dana Ann and Rob Slizik, Sr.,
and beloved sister to RI and Daniel Slizik

It is important to know bereaved parents cope with their loss in their own ways in their own time. A unique, individual journey. There is no right or wrong way.

“Our son, Killian passed away at 10 weeks from SIDS, 8 years ago. After the funeral and things settled down, it became increasingly painful for me to look in his room and see all of his belongings. Everyone copes with this differently. For some, they prefer their baby’s belongings to be out and accessible, but for me I needed them to be packed up in a special way. We have never hidden his existence and his pictures still hang on the walls of our home. So, I went out and bought a large wooden box. I stained the box and then stenciled a design on the top, including his name. I put everything in this box...dirty clothes with spit up on them, toys, birth and death cards, presents that were given to him, etc. At first I looked in the box often, smelled his dirty clothes and cried. As time has passed, I look in the box less, but always spend time with the box on his anniversary dates.”

Mary Vogel, in Memory of ~Killian Vogel~

Pre-Warning of Difficult Situations

Here are some situations that may be difficult or confronting:

- Celebrations
- Baby showers
- Birth of new babies
- Hospital visit of a new baby
- Being asked how many children you have
- Certain dates of pregnancy
- Age comparison with other babies/children
- Firsts: birthday, Christmas, Hanukah, Kwanzaa, Mother’s Day, Father’s Day, Halloween

You may be faced with attending events or celebrations that you just don’t feel up to attending. If this is the case, do not attend. If

you know attending will only leave you in tears or feeling worse, then it is not worth going. Hopefully, people will understand.

It is a good idea to prepare yourself and plan coping strategies for these occasions. These may include ways you might answer questions, how much you want to talk about your baby, preparing ways to leave early if needed.

We have come to hear many stories from all too many bereaved parents and they often talk of how those close to them and even acquaintances often just don't know what to say. It seems they then say nothing and do their best to avoid you or say the silly comments or put you in difficult situations. They may want to take your pain away or help fix it. If only they could know that 'it can't be fixed' but if they could just be there for us, being considerate and acknowledging our babies could make all the difference.

Pregnancies and Babies

You might be worried and anxious about seeing, holding or even being near pregnant women. Even just to hear a baby cry can be quite distressing. Put yourself first; protect your feelings and emotions. It is okay if you don't want to attend a baby shower or visit a new baby and parents in the hospital, or attend a child's birthday party. Hopefully, your family and friend will understand.

Subsequent Pregnancy

After the loss of a baby, many have told how their initial instinct is to want to be pregnant again. Some may not be able to conceive again and may feel they need extra support in their time ahead. A new pregnancy can be a stressful time for anyone but after losing a baby you always have that extra feeling of 'what if it happens again?' Many explain it that you are robbed of your innocence. Many women go on to have successful pregnancies, however for some a second or subsequent loss can leave you with a feeling of disbelief. Please know that you are always entitled to the very best of extra care. Don't be afraid to ask your doctor for more regular checkups, ultrasounds or tests. You may need consistent

reassurance throughout this pregnancy. If these things make you feel even a little more relaxed, it is well worth it.

Common Reactions to a New Pregnancy:

- Mixed emotions—being excited but so very scared at the same time.
- Feeling happy—creating a life is very special. It is okay to feel happy!
- Being very fearful—that something will go wrong with this pregnancy.
- Feeling anxious—of what the outcome will be or waiting on test results.
- Feeling frustrated—often explaining to people your previous experience/s can be very hard.
- Having difficulty in having faith/trust that things will be okay—even if this pregnancy does not have the same diagnosis of your previous pregnancy and loss.
- A feeling of being overwhelmed—there are so many things to consider with a new pregnancy.
- Feeling impatient—you just want to have your baby now, waiting 10 months seems like an eternity.
- Guilt—for those that may be around you who continue to have problems conceiving.
- An amazing feeling of being in tune with your new baby and not taking life for granted.
- Possibly still being fearful even once your baby is born safe and alive.
- Worrying about the new baby dying of SIDS.

Throughout your time of being pregnant remember that you might have good days and bad. There may be days where you are happy to buy baby goods and other days where you just can't face it. Know that this is okay. It is important you seek support if you need it from your partner, family and friends.

We are always here for you...

“Just when you think you’re doing
okay, the bottom falls out.”
Nikki in Memory of ~Isabella~

“If people make you feel uncomfortable by
imposing their thoughts or beliefs that conflict with
your own regarding the loss of your child, it is okay
to interrupt them and end the conversation in a
respectful way. Do not feel vulnerable to listen to
those who upset you.”
*Jerry and Amber Thomas, In Loving Memory of
~Baby Gavin~*



“A grief shared is a grief halved.”

Grief

The loss of a precious baby affects everyone in many different ways and can bring about different grief reactions in people. There is no right or wrong way to grieve. As long as you are not hurting yourself or others, it is okay. There is no set pattern of how you may grieve the loss of your baby.

Grief is often said to be like a roller coaster ride, of ups and downs and nice flat stretches as well. Here we have shared some grief reactions to let you know it is okay and normal to feel this way and experience these reactions.

Thoughts, Feelings and Emotions

Disbelief and Denial

When you are told here is something wrong with your baby or your baby has died it is hard to believe those words. Some families have said they simply didn't believe it and waited and hoped that it was not true. Sometimes families need to see for themselves that their baby has died. Disbelief and denial is said to be a natural protective coping mechanism.

Questioning

Why? Why me? Why my baby? How? What happened? These are very normal questions but ones that there may not be any answers to.

If Only's, What If's and Could Have Been's...

You might find yourself questioning things, going over everything leading u to the birth of your baby, and thinking forward wondering about all the could have been's, if only my baby was here, what if I went to the doctors earlier? What could it have been like to have my baby here with me now? You might find yourself asking and wondering if all of the if only's, what if's, and could have been's in the time ahead without your baby.

Coping

You may feel like you are unable to cope and not know how to get through another day. Coping with day to day life after the loss of your baby can be very hard work. You may be physically, emotionally and spiritually exhausted. Reach out and talk to someone, call for bereavement support from S.I.D.S. of Pennsylvania or one of the other resources listed in this book. You can cope and you can get through another day, but you may need some support to do so.

Feeling Numb

Many parents have expressed feeling numb. Feeling on the outside looking in with the world just going on and on. How can people act normally while I am devastated? Feelings of shock and numbness is your psyche's way of protecting you from the onslaught of emotions that are too painful.

Loneliness

You may feel very alone. Like you are the only person in the world that this has happened to. You may not know who to turn to or feel that you are alone in your grief. Please reach out to us or to other resources listed in this book. Talk to your good friends and family members.

Yearning

Many families tell of such a deep yearning to have their babies with them, to hold their babies close and to simply have them safe and alive in their arms. Yearning for the family they had hope and planned for. Some mothers say that their arms actually physically ache to hold their baby once again.

Anger

You might feel angry. Angry at the people around you, loved ones, life. This is a normal reaction, but please tell someone if this anger feels like it is overwhelming you. If you feel that you want to hurt yourself or others, please immediately call for help.

Blame

It is normal to want to find someone or somewhere to lay blame for the loss of your baby.

Fear

You may find yourself experiencing fear. Fearing normal situations that you had coped with in the past. Fearing that something may happen to someone else you love and care about. Fearing going shopping or facing people. It is normal to experience these fears but if you find them overwhelming and stopping you from doing the things you want and need to do, then please speak with your doctor and/or seek professional help.

Anxiety

Feeling anxious, nervous and worried can be a common reaction to grief. If your anxiety is interrupting your day to day life, please tell someone about how you are feeling and speak with your doctor.

Depression

Depression is a very serious and very real medical condition. It is not the same thing as sadness. It is important to be able to recognize the symptoms of depression and tell someone how you are feeling. Please seek medical advice.

Jealousy

You may find yourself experiencing some feelings that you would not normally find yourself experiencing. You may resent other women who are pregnant or have babies. This is normal to wish that you baby were with you.

Happiness

It is also okay to be happy. We often feel guilty if we are having a laugh or are enjoying ourselves. Don't feel guilty; remember you are human and just because you are feeling happy doesn't mean you have forgotten about your baby.

Triggers

You might find that certain things or situations trigger emotions that bring hurt, pain and tears. These triggers may affect you in the early

days to any time in the days, months or years ahead. It might be the weather, a scent, a song, a pregnant woman, a new baby, a twin stroller, the baby aisle in a store, a comment or conversation, a celebration, a holiday or it could be a special place you have visited.

It may look and feel to you that your family and friends will be just getting on and moving on with life—many bereaved parents say that once they experience the loss of a baby their life seems like it stops. This is a very true statement; however, we must acknowledge that life for others will go on. This can be hard as it may seem like they don't care but often this is not the case. Remember every day is a new day; to get through just one day is an accomplishment.

You do not have to make allowances for others' feelings and thoughts about the loss of your baby/babies.

Family and Friends

Grandparents may grieve for their children's sorrow and pain while grieving for the loss of their grandchild.

Family and friends may not know what to say or do, and so avoid talking about the loss of your baby altogether.

Family and friend shave said they wished they could take your pain and hurt away and therefore feel helpless because they can't.

Children may be fearful and clingy or act differently.

Children may ask many questions.

Children may be confused by the meaning of death.

Children may ask questions about where their baby brother or sister has gone.

There are many books in the library about how to deal with children and grief. Ask for suggestions or contact The Highmark Caring Place, A Center for Grieving Children and Adolescents. (See Resource section in this booklet.)

Coping Skills

It is important to try to take care of your physical and emotional well being—here are some suggested ways to help yourself.

Cry

It is okay to cry. No matter when or where. The release of your tears can often bring a good feeling. One of letting go and getting it out of your system

Talk and Share

Talking about your baby, how you feel, the thoughts you have can be very healing and helpful. Find someone you trust and feel comfortable with to talk with. It might be your partner, a family member, your friend or you might like to seek support from someone who has also experienced the loss of a baby. Talking about how you feel and what you are going through is helpful also as it gives those around you a deeper understanding of what you are going through and possibly ways of how they can be there for you. Seek professional counseling with a grief specialist who can give you a safe place to vent your feelings.

Support

You might feel the desire to connect with others who have experienced the loss of a baby and understands your feelings. You may refer to the back of this book to search for resources, call our office or join the online bereavement forum. Talking to others who truly understand your grief because they have been there is remarkably healing.

Journaling/Writing

Journaling and writing is a good way to express yourself. It may help you to make sense of your feelings. It can also be healing to write letters to your baby. You can then put them in a special box and save them. It is the process of being able to say all the things you wish you could have said or done with your baby.

Memories/Keepsakes

Honoring your baby with special keepsakes and making treasured memories can bring you much comfort by acknowledging your son or daughter.

Exercise

Try to get some physical exercise...go for nice walks and get some fresh air. Reconnect with nature. It can be a time of peaceful reflection or a way to vent anger or frustration.

Give Yourself Time

Time to grieve. Know there is no time limit as to when you may start to feel a little bit better. Go at your own pace and don't feel pressured by anyone. Remember to always do what is right for you and your family. You are the one living this.

Time Together

Spend some time together—go out to dinner, plan a weekend away, enjoy each other's company at home.

“The therapists at Child’s Way bought a brick at the zoo for
Jeremy when he died. It says:
‘Smile on us Jeremy Kindler’
I loved that because he was always smiling.”
Peggy Kindler in Memory of ~Jeremy~



Relaxation and Breathing

Trudi Penrose-Starr Dip. Prof. Couns. (Grief and Loss)
By Permission of The Teddy Love Club™ Pregnancy and
Infant Loss Support, Australia

I have had many bereaved families share with me their thoughts and feelings after the loss of the precious baby or babies.

One of the many things we have talked a lot about is how it is hard to sleep and the many thoughts running through your mind. How not getting enough rest and sleep can impact on the days ahead you are trying to face. We have also talked a lot about feeling anxious and having trouble being able to do the things that used to come easily.

I wanted to share with you a very useful and helpful relaxation technique. Something that you can call upon if you are having trouble sleeping or if you are struggling with feeling anxious about going to being places that never used to bother you. Also finding you haven't got the patience you did have and are looking for ways to cope and face the time ahead.

Find a quiet, comfortable place.

If you like music, play something that is soft and soothing.

Try to clear your mind.

Don't think of anything that is going on...

Breathe slow and deep

Let yourself sink into the bed/sofa where ever you are

Keep breathing slowly

Breathe in and squeeze your toes

Breathe out and release

Repeat

Breathe in and squeeze the muscles in your leg

Breathe out and release

Repeat

Breathe in and squeeze the muscles in your bottom
Breathe out and release

Repeat

Keep doing this all the way up your body, your back, your belly,
your shoulders...right down to your fingertips.

Keep breathing

You will be surprised how clear your mind has become. If you are having trouble sleeping and are doing this as you have gone off to bed, you will find that you can slowly relax into a nice keep sleep. The thoughts and feelings are still there, but you have just given yourself time to rest.

Quick Breathing Exercise

If you do not have the time to do the above technique, here is another quick breathing technique.

Breathe in and count to three in your mind
Breathe out and count to three in your mind

Repeat this for as long as you need.

Both of these techniques may not work for everyone and may not bring the same results for everyone, but I wanted to share them with you and do hope they will be helpful for you in one way or another. Warm wishes.

Trudi Penrose-Starr Dip. Prof. Couns. (Grief and Loss)



Returning to Work

“When I returned to work, I returned on a part-time basis, then after a few months, I decided to step out of my role and go to a job that had less stress. I think life really just came into perspective for me.”

Jaylee in memory of ~Kai~

Returning to work is often a hard situation and one that does not need to be rushed. Your decision to return to work is very individual depending on how you are feeling about your return. The thought of facing people and their reaction can be quite daunting especially if your work colleagues weren't aware that you were pregnant or possibly they were aware and you are not up to facing any questions or comments.

There are ways that you can prepare yourself for facing the questions and comments you may face. Once you have returned to work for that first time you might find the next won't be as bad.

Talk to your doctor about your return to work, they may recommend you return with fewer hours. Is returning with fewer hours an option for you?

Ask your employer what they can do to make your transition easier, ie., less hours, change to a position that has less demand or stress.

You could go into work to have coffee with a friend before you start; that way you have that first initial visit over. If you are finding it too overwhelming you can leave in your own time.

Talk to your human resource department/supervisor/director about how you are feeling about your return to work.

Think about what you do or don't want to tell people or talk about. You might find that the support from some people is really quite

comforting and you then feel comfortable in opening up with them. Go with what feels right for you.

Be aware that you may come across insensitive comments, opinions and expectations from others. Remind yourself that they most likely do not know what it feels like to lose a baby.

Take one day at a time—acknowledge that things may be hard in the beginning.

The most important thing is to always put your feelings first. Be kind to yourself—you deserve it.



“No one ever told me that grief felt so like fear.”
C.S. Lewis, *A Grief Observed*

Coping with Grief

“People would try to protect us by avoiding discussions/events about other babies or kids...(ie...not inviting us to another child’s first birthday party). Encourage everyone to treat you normal and not ‘protect’ you. Let your heart guide what you are and are not ready for. Likewise feel no pressure to attend or explain that this is hard for you.”

Jerry and Amber Thomas, In Loving Memory of ~Baby Gavin~



“Sometimes I bring a balloon to the cemetery and sometimes I don’t. It is hard to decide if I want to pretend he is still 2 (years old) and get him a Thomas the Tank balloon or to get him a balloon more in keeping with his teenage years. And would I be buying a balloon for a teenager? I don’t think so. I think that Jeremy’s birthday would always have been a special day for us. And by celebrating Jeremy’s birthday I keep a connection to Jeremy. That is the reason I buy a cake.”

Peggy Kindler in Memory of ~Jeremy~

To My Fellow Bereaved Parents...

Written by: Eileen M. Carlins, Mother of Matthew, Rachel, Sarah and Emily

“Time heals all wounds”.

How many times have people said those very words to you, trying to ease your pain? Is it true? Does time alone heal us? I believe it takes much more than time. It takes work so arduous that it cannot be described. It takes putting one foot in front of the other when you have no belief that there is solid ground before you. You walk on faith alone.

Thirty years have passed since our daughter, Rachel Ann, died at two months of age from SIDS. She was our second child, much loved and desired, and a lovely blessing in our lives. One fall morning, I laid her down for a morning nap, and 15 minutes later, she was dead—cruelly wrenched from her loving parents and family. When she died, I thought that my life was over, and could not comprehend how my heart continued to beat, or my lungs continued to take in air.

Others tried to comfort me—we have all heard the clichés:

She's an angel in heaven.

It's better that she died young, before you got to love her.

At least she didn't suffer.

At least you are young, you can have other children.

At least you didn't hear her say “Mommy”.

At least you have your son.

At least...it's better...it's for the best.

Did any of these statements ever help a bereaved parent? The only words I wished to hear were words that affirmed my secret belief that this was all just a terrible mistake, a bad dream, something bad that always happens to someone else.

In the midst of this pain, respite appeared in the form of other bereaved SIDS parents. Mothers and fathers, who had also suffered, but were now able to console others. They truly knew the depth of our pain, and did not minimize it, or try to explain it away. Yes, they told me that the pain would not last forever. I absolutely knew that they were wrong—

that my love for Rachel directly equaled the pain I felt now, and if I stopped feeling that pain, she would be lost to me forever.

What did time do?

Time relentlessly passed as I grieved and worked and wept and searched for answers. Did time heal my wounds? No, but as time passed, and as I worked at grieving Rachel's death, and channeled my energies into positive activities, such as support for bereaved parents, I discovered that there were good moments that did not negate my love for my daughter. The fight against anger and bitterness exceeded my expectations in terms of difficulty, and it seemed so much easier to succumb to that bitterness than to search for an alternative. To those mothers who supported me, I thank you for your time, your patience and your love. Without you I would have been lost. How can I ever repay you?

Which answers the question that is often presented to me: "Why do you still do that?"

I equate the time I have spent on SIDS to the time I would have spent with Rachel. I attended all of my other children's sports activities, parent teacher conferences, piano recitals, rocked them to sleep, read them bedtime stories and loved and kissed them tenderly. The time I did not have with Rachel is the time I offer to other bereaved parents. We have the gift of time. How do we choose to share it? A gentle voice comforted me at the darkest moment in my life.

I am here for you.



A Bereaved Parent's Wish List

1. I wish my child hadn't died. I wish I had him back.
2. I wish you wouldn't be afraid to speak my child's name. My child lived and was very important to me. I need to hear that she was important to you also.
3. If I cry and get emotional when you talk about my child, I wish you knew that it isn't because you have hurt me. My child's death is the cause of my tears. You have talked about my child, and you have allowed me to share my grief. I thank you for both.
4. I wish you wouldn't "kill" my child again by removing his pictures, artwork, or other remembrances from your home.
5. Being a bereaved parent is not contagious, so I wish you wouldn't shy away from me. I need you now more than ever.
6. I need diversions, so I do want to hear about you; but, I also want you to hear about me. I might be sad and I might cry, but I wish you would let me talk about my child, my favorite topic of the day.
7. I know that you think of and pray for me often. I also know that my child's death pains you, too. I wish you would let me know those things through a phone call, a card or note, or a real big hug.
8. I wish you wouldn't expect my grief to be over in six months. These first months are traumatic for me, but I wish you could understand that my grief will never be over. I will suffer the death of my child until the day I die.

9. I am working very hard in my recovery, but I wish you could understand that I will never fully recover. I will always miss my child, and I will always grieve that she is dead.
10. I wish you wouldn't expect me "not to think about it" or to "be happy". Neither will happen for a very long time, so don't frustrate yourself.
11. I don't want to have a "pity party", but I do wish you would let me grieve. I must hurt before I can heal.
12. I wish you understood how my life has shattered. I know it is miserable for you to be around me when I'm feeling miserable. Please be as patient with me as I am with you.
13. When I say "I'm doing okay", I wish you could understand that I don't "feel" okay and that I struggle daily.
14. I wish you knew that all of the grief reactions I'm having are very normal.
15. Depression, anger, frustration, hopelessness, and overwhelming sadness are all to be expected. So, please excuse me when I'm quiet and withdrawn or irritable and cranky.
16. Please excuse me if I seem rude—certainly not my intent. Sometimes the world around me goes too fast and I need to get off. When I walk away, I wish you would let me find a quiet place to spend time alone.
17. I wish you understood that grief changes people. When my child died, a big part of me died with him. I am not the same person I was before my child died, and I will never be that person again.
18. I wish very much that you could understand—understand my loss and my grief, my silence and my tears, my void and my pain. BUT, I pray daily that you will never understand.

(Author Unknown.)

How Do You Tell People Your Baby Died?

By Kathy Whelan

Reprinted with permission from the Massachusetts Center for SIDS

About three weeks after my son died, I decided to go to my step aerobics class. The class included women who had seen me three times a week while I was pregnant, up until I gave birth. I didn't socialize with them other than at the health club. I went there knowing that people would assume that I was still caring for a four-month old child. How could I bear to tell them that he died? To watch their mouths drop in disbelief. To feel them struggle for words. I decided not to tell anyone, and as the class progressed, silent tears pooled, and I became over-whelmed with sadness. I left the class, sat in the car with the empty car seat, and sobbed with abandon. I struggled with this problem often over the next few years. I feared situations where I might run into people who didn't know that my baby died: friends at a college reunion; a business associate at my former place of employment; people I knew from my summers on Lake Champlain. I avoided those situations at all costs.

What made me so fearful of confronting situations where I had to tell people my baby died? Because I had to say it out loud. Because I had to look at their shocked faces. Because I feared being branded as "a parent whose baby died." Most people can't understand how a parent can survive the death of a child. They don't like to think about it, but they have to say something.

I was afraid of what they would say, but I was also afraid of how I would feel telling them. I felt wounded. Different. I used to be so happy-go-lucky. Carefree. Mikey's death had totally changed me into someone I did not recognize. I felt like a walking sideshow, even if most of my mourning was inside. I looked normal, but my insides were torn apart.

If you have any expectations of what someone might say when they find out about your tragedy, you might be disappointed. It takes their breath away. Many manage "I'm sorry." Often people will find a way to exit an un-comfortable situation, and not always

gracefully. Even those who know your child may avoid you. It's not that they don't feel sad; they just don't want to bring it up. They want to help you, but they just don't know how. They fear they will cause you pain. They don't understand that you need people to acknowledge your child and your pain. It's just too hard for them to do.

Once in a while you meet a rare person who wants to know more. Who can swallow their shock at the news and ask to hear your story. They let you say your child's name again. Those people allowed me to openly grieve about my son and became very important to my healing. I knew I was safe in expressing my grief to them. Once was a close friend from college. Another I met at a play date for my second child. And a third I met when she had a miscarriage, and I asked her the details.

How do I decide to tell someone that my baby died? At first I told anyone who would listen. After negotiating many very uncomfortable social situations, now I wait to see if the person in front of me is someone who can handle it. Is it someone that I am going to have an on-going relationship with? Is it someone who is grieving and might be helped by knowing that people survive this most horrific of tragedies? Do I have enough time and privacy to spend fifteen minutes talking to this person?

Once I decide to tell someone, how do I find the words? Usually I wait until we are having a personal conversation. Maybe we are talking about our children. Or I mention my volunteering for SIDS. I tend to put my hand on the person's arm to steady myself and get their attention. And then I blurt it out, the same way I have. "I had a son that died." In that uncomfortable silence when the person I've told is digesting that fact, I tell them his name, his age, and how he died. I talk about the support, how I've lived all these years, missing him, but living still.

Whether your baby died last month, or thirteen years ago, it's always hard to tell people that you had a child that died. Like any human interaction, it's a bit risky. You can't tell how they are going to react, and whether or not you will be able to handle their

reaction. If you do decide to take that risk, you may find someone who can help to share your burden of grief by letting you talk about your loss. Or at least, you can give the other person permission to help you by expressing their sympathy.

“Losing a child becomes part of who you are. It never
‘gets easier’.”

“If you feel overwhelmed, we encourage you to seek
help in a support group with other parents who have
experienced a similar loss.”

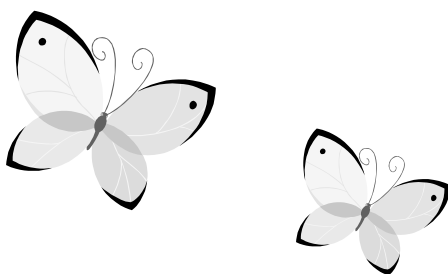
Jerry and Amber Thomas

In Loving Memory of ~Baby Gavin~

The Time Ahead:

“It’s more than the loss of your baby, loss of chance at
motherhood, loss of being blissfully unaware. Healing takes time
but it also needs you to create the right conditions: get up, eat,
and be open to dealing with your grief.”

Nikki in Memory of ~Isabella~



Putting the Pieces Together

John Hyter, M. Div.

Sheri Bradshaw is a SIDS mom from North Carolina and former Program Coordinator for the SIDS Alliance in the Carolinas. Her daughter, Catherine, died in December of 1994. Sheri and I met at the National SIDS Conference in Dallas two years ago, and we have corresponded occasionally since then.

We have recently been discussing the struggle we all go through trying to understand the grief healing process. Sheri says, "It's like the pieces of life have become a new jig-saw puzzle. First you find the edges and make a complete enclosed border. The hard part is filling the inner parts. In grief work, the 'inner' is the hardest."

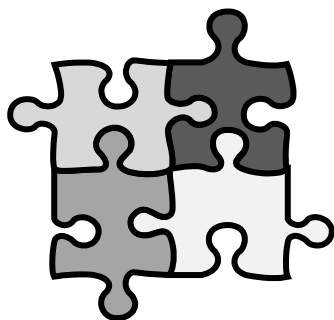
Many people who have not been through grief have a hard time understanding what it is like. They often see the part of ourselves that we show others—the "border" Sheri talks about—and think we are doing fine. We are "over it" and moving on. They have no idea what is happening inside. Grief healing is not getting over our loss. It is learning to live *with* it, learning to live *around* it, and learning to live *in spite* of it.

Learning to live with it. At first, the pain of our grief may be so strong that we have a hard time functioning at all. Some days we may not be able to sleep. Other days we don't want to get out of bed. We may lose our appetites and not want to eat. We can't seem to concentrate on anything. Sometimes we can't remember what we started to say or how to do the simple things we always did before. The pain of our grief gets in the way. But we have to do all the ordinary things in life anyway. We have to go to work, do the laundry, balance the checkbook, and take care of the rest of the family. So, the first thing we learn is how to do all these things while we are in pain. We learn to live with it. We have built the border of our puzzle. That is part of healing.

Learning to live around it. After a while the day-to-day pain loses its edge. We have learned to live with it like the

constant, dull, ache of an old injury. But, like an old injury, it can get aggravated from time to time and the pain comes back with a vengeance. Sometimes it seems to come out of nowhere and takes us by surprise. Sometimes we can anticipate it, like on holidays, birthdays, anniversaries, and such. Eventually, we learn how to deal with these “flashbacks.” We adapt to them and adjust our plans to take them into account. In other words, we have learned to live around the wound our loss has created in our hearts. The middle of the puzzle is beginning to take shape. That is part of healing.

Learning to live in spite of it. Even though it may not seem possible if our grief is new, the day will come when we will feel joy again. We will laugh and have a good time again. Some of us feel guilty when this happens. We think feeling good means we have forgotten our baby and we are dishonoring his or her memory. The grief over our loss is not gone, but it isn't as close to the surface as it once was. We have just learned to live life to its fullest again, in spite of our loss. The puzzle is complete, and that is healing.



What If I?

Leslie Mersinger in Honor of ~Austin~

When a tragedy happens we wake up and wonder what if I...

...what if I had done something different?

...what if I did something wrong?

We ask ourselves these questions along with others.

Our emotions spin out of control and we feel so empty.

Every day is a new beginning we may wake up to a thought or
feeling overwhelming.

In the back of our minds we still wonder what if I...

Sometimes things happen and we question our faith, but in each one
of us God had fate.

God had a reason for everything done.

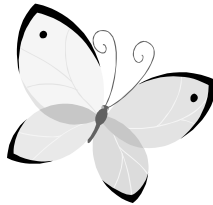
In our hearts our lost loved ones live on.

One sweet day at those glorious gates they will want with open
arms.

As we live out our lives and do what we were destined to do, for

God our father gave each of us life for a purpose.

So the question we ultimately should ask is, "What does God have
in store for us?"



For Italia

An Italian princess
that was given to me
was taken away
as fast as can be.
I miss your face
and the way you cooed at me
but in my heart it was never meant to be.

Ti Amo Bella Italia
From Berezanich and Laird Families

To Connor:

Michelle Longmore in Honor of ~Connor~

So tiny. So small
yet precious as could be
Our little boy Connor
That was you.

Pulled from my body too early
it wasn't your fault or mine
We had a chance to get to know each other
only two weeks of time.

Now you're with Jesus
Our little angel
Connor we love you and will
never forget you.

Love,
Mommy and Daddy
XOXO

If I Go to a Therapist Does it Mean That I'm Crazy?

Ann Petrila, L.C.S.W., M.P.A.

It seems like in the movies only the very rich or the very disturbed are in therapy. Like so many messages from Hollywood, this is one that is not particularly helpful. While it is true that some types of therapy are designed for those struggling with serious mental health issues, there are also many other reasons that people might find themselves in a position to benefit from counseling or therapy. One of those times is certainly the unexpected death of a baby.

A traumatic event like the death of a baby from SIDS (or any other reason) leads to a number of painful and seemingly unbearable feelings and emotions. Most of these feelings fall well within the range of a “normal” or “typical” reaction to this unthinkable event. Even though emotions or thoughts might be very typical, they also might feel unbearable to a parent or other family members. As we so often discuss, there is no right or wrong way to grieve a baby’s death—there are no “shoulds” or “should nots.” There are, however, some “red flags” to which we want to pay attention that signal a need to consider getting some outside help with the grieving process.

While the pain of a baby’s death always feels unbearable, there are times when the pain seems like it might destroy you. If the pain is too great or does not subside in a way that you can stand, it might be time to seek counseling. Even though it is a very individual decision about the pain being too great or being unmanageable, you will be the best judge of your own feelings.

What might contribute to this unbearable pain that does not cease? How might you know if you could benefit from counseling? The following is a list of situations and behaviors that may signal a need for further intervention. Please remember that all of these feelings and actions are typical when a baby dies. It is the

degree and intensity of the feelings, and whether they feel manageable or tolerable that may cause concern.

If you find that you are experiencing:

Extreme sleep disturbances

Anxiety attacks

Deep chronic sorrow that never changes

Unable to get out of bed for days on end

Extreme temper outbursts

Severe, long lasting appetite changes

Paranoia

Increased drug or alcohol use

Extreme, ongoing anger

Use of prescription drugs in a way that feels uncomfortable

Relationship difficulties

Suicidal thoughts

Uncontrollable sobbing that won't stop

Homicidal thoughts

Many people that you trust are suggesting counseling (which is different than the "get over it" message)

As mentioned above, all of these behaviors and feelings (though very painful) are part of a typical grief response. Grieving parents frequently hear the message from well meaning friends and family that their grief is abnormal if it is too strong or has gone on for too long. That is not the message intended here. Even though everything on the list can be experienced by grieving parents, it is the strength of the feeling that must be addressed. If you, or those around you, feel like you are struggling in a way that you cannot manage alone, it is well worth considering talking to a therapist.

When grieving people do consider counseling, oftentimes "self talk" or statements that are made in one's head can get in the way. Statements like, "I shouldn't need a crutch to get through this," "I've always been so strong before and able to handle my own problems," "Why should I have to pay someone to listen to me?" "Talking to a therapist will not bring my baby back so what's the point," or "If my faith was stronger I'd be better by now" are

examples of negative self-talk. Do any of those statements sound familiar?

It may be true that you *are* a very strong person and that you *have* always handled your own problems in the past, but it is *also* true that nothing has prepared any parent for their baby to die from SIDS. Most parents struggle more with their baby's SIDS death than they have ever struggled before. There is no comparing the grief brought on by the sudden, unexpected death of a baby to any other grief experience. Therefore, all those statements about functioning in the past or handling other difficult situations are in fact meaningless. There is no practice for SIDS-related grief. If family members find themselves wanting or needing "extra" help coping with their grief, their relationships or anything else related to a baby's death, it is very understandable, and actually to be expected.

So, the answer to the question, "If I go to a therapist does it mean that I'm, crazy"? is a resounding NO. It means that you want some help in handling a situation that is horrible and unthinkable. It means that you have decided to do something that will help you through dark days that seem to have no end.

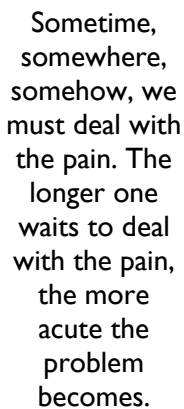
"I have always felt Samantha Ann has given me a special gift. A gift to help others. I have devoted the last 7 years to wanting to make a difference for people and I feel I have done that in many ways. Helping other parents, fundraising in her memory, and helping with getting a bill passed. The Missing Angel Bill.
Dana Ann Slizik in Honor of ~Samantha Ann~

Taking Care of Yourself

In caring for ourselves, we need to identify those activities that are healing to us as well as those areas that may hinder our healing and cope with each appropriately.

- Give yourself permission, time, and space to grieve.
- Don't pretend that death doesn't hurt.
- Feel free to protest the "why" of the death.
- Don't judge your level of grief and healing by how others are grieving and healing, but by your own internal awareness.
- Understand and accept your limitations
- Respect your spouse or partner's timetable and method of grieving.
- Don't escape into loneliness.
- Get rid of imagined guilt and "if onlys".
- Laughter doesn't mean you are being disrespectful to your child's memory.
- Confront the fears of your death and the death of other loved ones.
- Cry.
- Honestly express your feelings about this death to people who will understand and not be judgmental and who will not be hurt by your honest expressions of feelings.
- Recognize that seeking professional counseling doesn't mean that you are weak, inadequate, or crazy.

- Use religion, philosophy, poetry, music, art, gardening, tennis, walks at nature centers, reading, volunteer work, to gain relief and understanding.
- Talk about your experience to friends who were involved, and to friends who were not involved with the death.
- Accept your friends with all their imperfections and occasional bad advice, for you too, have your moments of imperfection.
- Tell others what you want from them: help, emotional support, time sharing.
- Continue to participate in activities that are fun for you and with people who are special to you; don't underestimate the effects of small pleasures.
(Author unknown)



Sometime,
somewhere,
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The Only Way is Through

By Dr. James Burge

It has been said “pain is nature’s way of telling us that something is wrong.” Well, that may be excellent textbook information but “down where the rubber meets the road,” we know there is something wrong. What is needed is relief. It would be so simple if medication could be given to eradicate the pain but medicine merely postpones the pain. Sometime, somewhere, somehow we must deal with the pain. The longer one waits to deal with the pain the more acute the problem becomes.

- Pain is not a generic term. I don’t believe for a heartbeat that one can go through life without pain. On the other hand we all know of those who thrive on what they call pain. This is not to be misconstrued as minimizing one’s pain but there is a vast difference in real and imaginary pain.
- The pain suffered by the death of an only child or all children is one of the most serious pains we face. When our child dies we aren’t dealing with a single pain but a complex combination of pains. As soon as the news of the death is realized, the body reacts in a protection mode, immediately releasing a series of chemicals. Some of these chemicals can react within the body for weeks, even months. Others form a kind of chain reaction. Therefore, if the person were totally able to cope with the situation surrounding the death, he would continue to be in the process of recovery for a long time. Research has proven that one must go through a series of anniversaries before fully accepting the fact of death. Regardless, one NEVER “gets over” the child’s death; we merely learn to tolerate what death has done to him/her. Pain is real! Psychologists are telling us 85% of the people in the hospital for medical purposes, are there as a result of unresolved grief matters. Unresolved grief is pain.
- Some years ago I had the privilege of attending a seminar led by the noted psychotherapist, Dr. Jan J. William Worden,

Ph.D. The nerve center of this particular lecture was the fact we cannot avoid all pain but in order to get out of it we must go through it. Did that fact drop like a bomb shell!! He continued to explain there WILL be times when we think we are going under for a third time. Our mood swings WILL go from acceptance to denial to acceptance again. It WILL take TIME, but we will recover.

- Caregivers must be constantly alert to assist the griever in dealing with pain, not to become another source of pain. By this I mean, a caregiver needs not know all the “facts” surrounding any given situation. Our role is to be there, physically when possible. This is must easier to say than do. Our presence silently says, *“I am with you in your pain. I need not know how you feel. I will not judge you or your actions. I do not come as one with answers; I come as a friend who cares.”* This is empathy! One cannot empathize and escape shared pain. A grieving heart needs assurance of the presence of another.
- Sympathy is not enough. One can show sympathy with a card or other gestures of acknowledgement. Feeling sorry doesn’t cut it! With all these gracious acts of kindness the griever still cries. “Touch me, hold me, I don’t have leprosy. Cry with me. Don’t be fearful of my situation. Just walk with me through it.”
- Throughout the years dealing with grieving people, the most frequently asked question has been: “Will I ever get over this pain?” It is by far too simplistic for a one word answer, but the fact remains...”Yes, you will.” Right now, that pain may be so severe you see no end. As you are reading this article you may not see yourself as “healed.” You have more questions than there are answers. Understand, my friend, you are quite normal. Accept these difficult times as part of the tragedy of death. Allow your friends to be part of your grief. Understand they too are looking for “the right words.”

NEVER FORGET, THE ONLY WAY IS THROUGH!

Excerpted with permission from Alive Alone by Dr. James Burge

“How Many Children Do You Have?”

By Joani Nelson Horchler

In learning to live again, you will venture out into work and social worlds. You are likely to find that these worlds feel divided into two groups: those who know about your loss and those who do not know. Both can be tiring. You may find yourself longing for people who do not know, who can let you forget your loss (but never your baby) for a moment or two. And yet, those who do not know can create the dread of that almost unbearable question, “How many children do you have?”

There is no right or wrong answer to this question. You will answer according to what makes you feel the most comfortable. Ruth Skopek’s response is, “I’m a mother of five, raising four of my children.” My usual response is “I have four daughters and also a son who died of SIDS.”

Whether a parent includes the dead child in the count depends not on the parent’s wish to forget the child, but more on the emotional investment he or she wants to make in the person with whom he or she is talking. If it is a casual question from a grocery store clerk, the parent of two living children and one dead child might say he or she has two children. However, if the question comes from a new co-worker who is likely to learn eventually about the lost baby anyway, the parent might answer three, with an explanation, in order to establish a firmer and more personal relationship with that person.

If your only child died, you grieve not only for your lost baby but for your lost role as parent. Are you still a mother or father? Of course you are. You always will be. But only you can decide how you want to answer the question, “Do you have children?” When interviewed, many SIDS parents say that they do answer yes in most cases (though they frequently answer no when the question is from someone they will likely never see again). You may find yourself tailoring your reply to the situation and your own inner needs at the time. Whatever your reply, know that for the time being the honest answer is the answer that makes you most comfortable.

Eventually you will find an answer that makes you feel loyal to your baby, to your emotional needs, and to the person asking the question.

Relationships

By Permission of the Teddy Love Club™, Australia

The loss of your baby can often put a significant stress on your relationship with your partner. You have both experienced such a sad loss and the time that follows can often be full of good and bad days. Know that this is normal—you cannot expect that everything will always be as it used to be. This does not mean you don't care for each other; you are both going through something parents should never have to.

Parents have told us:

“Our relationship became stronger than ever; we relied on each other so much.”

“We argued a lot; I think there was so much we didn't talk about when we should have.”

“We talked more than we ever have before. I saw a side of her I had never seen before.”

“We both went to counseling. We were skeptical in the beginning but it really made a difference.”

“If we can get through this we can get through anything.”

It is important to try to talk with each other and express the way you are feeling.

Grief of Couples

By Ann Kincaid, ACSW

When a child dies each parent begins to deal with grief in his or her own way. Some openly express their feelings, crying often and talking freely about their thoughts. Others immerse themselves in work or daily routines and decline to discuss their feelings at all. Parents differ also in their feelings about visible reminders of the baby—for example, whether keeping the child's room intact is comforting and maintains a feeling of closeness with the baby or if it is too painful a reminder of the loss.

Couples often find that grief affects them in opposite ways at any given point in time. It is common to hear couples give the following description of their experience. Initially, one parent may feel overwhelmed by grief and can do little but cry and talk with others about feelings of shock, disbelief, anger, loss, their memories of the baby and of the day of the death. Their partner, on the other hand, may begin to take charge of arranging the details of the memorial services, notify family members, make any necessary decisions, and soon lose themselves in work. One parent may find it very important to be able to go to the child's room and see pictures of the child while the other may avoid any visible memory of the baby.

As the parent who has been openly expressing grief begins to feel better and can resume daily activities, the other parent often feels that they can no longer maintain their pace. They start to feel that they are only going through the motions of work and find themselves suddenly overwhelmed by feelings of anger or sadness. They often worry because they thought they were doing so well and see themselves as losing control.

Throughout this initial period of grief parents also search for a reason for their baby's death. This may take the form of looking for a medical cause for SIDS. They may review articles and research publications about SIDS in hope of finding evidence of a specific cause. They may also try to understand some meaning for the death and for awhile may worry that this is in some way a

punishment for them. Again, couples often find that while one parent swells on this, the other is feeling that this is a useless pursuit, thinking that finding an answer will not really change anything. Then at some point the feelings reverse so that the first parent begins to come to terms with the loss while the second starts to question why their baby had to die.

Unfortunately, these different paths people take through grief can lead to misunderstandings and a sense of isolation. The person who starts out expressing their grief can begin to think their partner doesn't care or can become angry with their partner for hiding his or her feelings and not talking or listening. The person who is trying hard to "get on with life" may worry that their partner may not recover.

Actually these opposite coping styles of some couples may service to function as they grieve. Couples will often recognize their efforts to strive for this balance in statements such as "It's been a terrible week. We've both been really down. We couldn't help each other and nothing got done." They often see the swings in feelings as they say such things as "I had to be strong and keep things going but now I can't anymore", or "I saw that my husband was beginning to have a really hard time and I knew I had to pull myself together."

It helps to avoid misunderstandings to know that each person goes through the grief process differently and that for couples the different feelings often serve as a way of allowing time and support for the other to express their feelings.

"At one point you will feel like you have no emotion and that you are unable to cry...don't feel guilty...you are normal! We both experienced this. Maybe it is the overwhelming feeling of shock. Others may perceive this as 'you are handling your loss very well'...don't feel guilty if you cannot share a good cry...we refer to it as the "stone stage"."

Jerry and Amber Thomas, In Loving Memory of ~Baby Gavin~

Helping Couples Cope

By Darla Harmon

By Permission of the San Diego Guild for Infant Survival

I wanted to shout at my husband, "You don't hurt like I do!" It seemed to me that he wasn't hurting because he held his feelings inside. I was angry and wanted to say something mean, so I could see the pain in his eyes like the pain I felt in my heart. Luckily, I didn't say it.

There were few things that threaten the well being of a marriage like the loss of a child. The deep sadness, self doubt, anger and lack of control are difficult to deal with, and greatly impair our ability to be a good spouse. It is common knowledge that men and women cope with emotions in different ways, but we must also consider that people grieve according to their personality. Quiet people will grieve quietly and outspoken people will find comfort in talking. But there is must more to a personality than being quiet or talkative, and all of those things will come into play during grief. I remember feeling close to my husband soon after our daughter, Rachel died, but then a few months later it seemed like we went in different directions. My husband had to keep busy as a way to cope with his grief and I was physically and emotionally exhausted, and sleeping seemed like the only escape. We both had to find ways to help ourselves, and communicate with each other about what we needed.

How do you hold your marriage together during this difficult time and be sensitive to your spouse? Here are a few things that may help:

- Allow each other to find and do what helps make them feel better. You don't have to grieve in the same way.
- Acknowledge that you are both hurting very deeply although it may be outwardly hard to see.
- Realize that you can't remove your spouse's grief or fix all of the problems. It is a process you will both have to work through.

- Tell each other, friends and family what helps you. People don't instinctively know how to help you. It is okay to ask for help or comfort.
- Come up with a "code word" to signal your spouse that you are having a bad day and struggling with your grief. It is helpful for your spouse to know when you are apt to cry or become angry at the least little thing due to grief. Try to recognize when this is happening and use your code word. For example, if you are feelings especially upset or irritated, tell your spouse "I am having a baby day". They will know what is truly wrong and do their best to make things easier for you. This is also helpful when you are out somewhere together and one of you desperately needs to get away from a situation to keep from falling apart. Working as a team benefits you both.
- Express your current limitations. If you are weary of being a listening ear, or you just can't attend church or a family gathering, be honest yet gentle.
- Be aware that your family is grieving also. They may not act as you would expect or may do something hurtful, but they are grieving and unsure of what to do.
- Seek support together and apart. Reach out to friends or family or to someone new that can help you. Attend a support group. Hearing stories of other parents helps to ease your pain. You won't feel so alone and other parents genuinely want to meet you and be of support to you.
- Realize that it is okay to be angry. This is a common feeling. We don't understand how this could happen to us and it seems so unfair.
- Remember that you were a couple to start with, and the dear child you lost, was born out of that love. Be sure to nurture each other and your relationship. You both need it more than ever.



For Men Only

By David, Delgadillo, SIDS Father

By Permission of the San Diego Guild for Infant Survival

My son died of something that is called Sudden Infant Death Syndrome. Twenty seven days before he died, I was proud. Our first child and this little creature of God was a boy. Now, I had told my wife, "it really doesn't matter—boy or girl—I'll be happy with either." But, you know, it did matter. In my mind I saw a son to carry my name—and a part of me—on through the years. I had a son to do things that other fathers do with their sons: explore, baseball, camping, man-to-man talks and so much more.

Then the terrible happened. On a cool September evening he left. Strange, to come into this world struggling and crying only to leave it without so much as a whisper of a shadow. For the remainder of that evening my heart was purged of feeling. Shock at the unthinkable—a baby had died.

That night was simply a prelude to the grief word which was to come. Grief, in part of its manifestations, forces a man to look at himself. He questions who and what he is. He attempts to deal with the loss the best he knows how. Many times the best he knows interferes with his life and the lives of those around him. In part the following is a story of men, a story of thinking about the dead and the living—and choosing.

How We Get to What We Are

It has been said that 99% of humankind's existence on earth has been spent hunting or gathering. Man's job is to go on the hunt, women's is to care for the children. The Industrial Revolution is relatively recent in the scheme of life. Perhaps our history may help to explain in part why men deal with grief differently than women.

Little boys and girls are treated differently as they grow. Boys are encouraged to enter competitive competitions, to learn how to take and to be the King of the Mountain. Boys are Ninja Turtles and Space Heroes. Girls learn to take care of Barbie and her various belongings. They learn social skills much sooner than little

boys. Little girls are allowed to cry more often than the “little man of the house.”

Children also learn from observation. They see many examples of “do as I say and not as I do”. They learn that mothers may weep while fathers remain stoic and guide the family through crisis. It is true that times are changing. Nevertheless, the force of culture is quite persuasive when it comes to raising our children. If we take a close look at our values we find that they are conservative and similar to those of our parents. The point of all of this is that parents do raise their children with differing expectations and outlooks for their children’s future.

How We Are Now

I spoke to some fathers whose children died of Sudden Infant Death Syndrome. One, upon returning to home from his daily job, would begin to work again. He was building an addition to the house. To bed after midnight and up in the morning for more of the same. With a smile he related how he had completed the addition in less than a month. “We had a nice new room, but I still hurt inside”. Another father remained quiet about his grief. He cared for his family and wife. Outwardly he remained above the pain. But, in the morning, while driving to work, he would park his car and cry. Both fathers along in their grief—not letting anyone enter.

Men are taught both in word and example to be a certain way while they are small children. Those values become roles and ways of behavior in the adult male. They include: stoicism, competition, protector and provider for the family, problem solver, controller of environment and emotions and to be self-sufficient. The death of a child may affect all these roles in adverse ways. Stoicism increases, guilt is magnified, self-esteem is crushed and control is lost.

By way of contrast, most women are more open with their emotions and are able to share feelings on an intimate level. They have friends with whom to talk. Women will accept counseling more easily than men. Women are usually able to do their grief work readily while men struggle from one level to the next.

How We Might Be

Grieving is a way to put our world back together. Grieving heals the open wounds left by the death of our child. This healing comes about by the expression of emotion and talking. Emotion left buried stagnates and festers. Unresolved grief may cause serious emotional and physical problems. Many men have to and must relearn roles which will encourage the expression of grief. These relearned roles include:

- **Talk to Your Family**

Don't leave your wife out. As mentioned above, two may bear the stone of grief much easier than one. Spend time together with her and your other children. Let them know you are doing what you are able to do, that you want them to help.

- **Have Quality "Alone" Time**

Sort out the millions of questions tumbling about in your mind. Think about your loss. Figure out the "What's" and "Why's". Gradually answers will come. Consider the use of a journal and write down your thoughts. As the days go by, read what was written before.

Decrease Social Activities

Many men will look for new hobbies or social activities. This only serves to take time away from grief work. Back off from added responsibilities. Remember, you really cannot back away from memories. Give yourself the time that is needed for grief work.

Cry

Crying is an effective way of dealing with the painful emotions of grief. Many men will have difficulty with crying. It may be okay to do so during the funeral but what about at home? Don't suppress the lump in your throat or tears that want to come. Crying actually makes one feel better as though some tension has been released from within the body.

Express Anger

Express your anger in constructive ways. Ignoring or denying anger does not make it go away. It is difficult to decide with whom to be angry. Neither wife, paramedics, nurses, nor doctors caused the death of a SIDS baby. Some have said that it is okay to be angry with God, that He or She is big enough to take it. Speak with those involved with the care and transport of your baby. Let them know how you felt about their attitudes both positive and negative.

There are many ways to express anger in physical ways which are not harmful to yourself or others. Exercise is one way. Body movement and the awareness of how you feel during movement may be helpful.

Find a Support System

This could be the hardest for a man to do. To admit to others that he needs help. I think it is easier to do if you look for other bereaved fathers. Fathers who have gone through the same thing you are now experiencing. Parent Support Meetings may also help to see how other families in various stages of grief are coping.

What a Support Group gives to you is the knowledge that you are not alone—others have been there also.

How We Know We're Making It

"Time heals all" is a common cliché that is heard. This is true only in part. Time, Work, and Knowledge help to heal. So, how do you know you're getting better? The following are some ways to assess the outcomes of your grief work:

- You become less inward. You look out of yourself and see how others in your family are dealing with the loss.
- You are able to live with yourself and the emotions within you. You learn more about yourself and the intensity of emotion is lessened.
- You have times without emotional stress. There is freedom of thought and joy in thinking about other things. This should not make you feel guilty, you are or betraying the memory of your child—simply learning to live with it.

- You become more comfortable with your grief. Ups and downs begin to stabilize and you are able to talk about your loss.
- You begin to feel less depressed. Depression may manifest itself as anger, anxiety, indecision, helplessness and physical disturbances. Do not confuse sadness with depression. Sadness does not disturb your daily activities.
- You begin to act in traditional “manly” ways. You become more sure of yourself. The concern is that these male roles do not become a shell to protect you from the pain of grief.
- You realize that you and your wife or partner did your best. There is no blame.
- You begin to see meaning in life. You begin to laugh and enjoy life.

For Italia

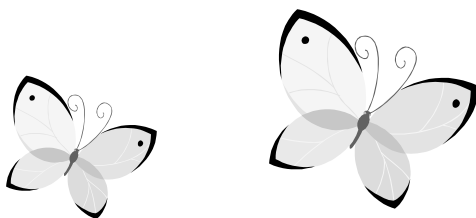
My little angel so soft and cute
 why did the lord take you away so soon
 My little angel so soft and neat
 mommy fed you washed you and kept you clean.
 My little angel so soft and precious
 I wish like heck you still were with us
 My little angel so soft and sweet
 every day I get on one knee.
 My little angel I miss you so much
 I would give anything in this world to feel your touch.
 My little princess every day you are missed and
 every day I wish I could give you a kiss.
 My little queen I guess this is the end
 and one day we will be together again.

- We love you Italia and miss you so much.
 Love always - Emily, Austin, Anthony, Mommy, Daddy,
 Grandma, Grandpa, and Aunt Amber.

One More Day

If I had one more day to share with someone it would be my son, Luke, who recently left us at the tender young age of 4 months. The day would be a Saturday and it would start as any ordinary day—him waking up with a huge smile, me signing good morning to him and feeding him breakfast. But this day I would hold him a little tighter, kiss him a little more, smell him a little harder, and stare at him a little longer so I could memorize every detail of his beautiful face. I would read him all the books I never got to read him and sing him all the nursery rhymes I never got to sing. The only time I would put him down would be to give him one more bath so we could play a little longer while I'd sing 'Splish Splash I was Taking a Bath', like I always did. Hoping that I would get the biggest smile that sweet little face could give. Then I would put him in the pair of pajamas that he never wore because I was saving them for a special occasion. Then I would hold him and rock him to sleep by signing our good night song 'Hush Little Baby Don't Say a Word'. I would sing all the verses like I always did. Then I would whisper over and over, over again that I loved him and I would never, ever, ever, let him go. The last thing is I would make sure my husband was home so we could spend our one more day as a family.

Heather Martin in Memory of ~Luke Martin~



Children and Grief

Stages of Grief in Children

Written by Susan Moore, M.A.

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Once children have been given an explanation of what has happened, they must still deal with their grief. The child must work through the three stages of grieving:

- **DENIAL** shock, numbness
- **ACUTE GRIEF** sadness, depression, anger, guilt, Anxiety, fears, regressions, physical distress
- **ADJUSTMENT** painful acceptance of reality; re-establishment of life

There is nothing in the life of children to prepare them for death. While children pass through the same stages of grief as adults, because of their limited life experiences, they will grieve *differently* than adults. It is important to remember that every person and child grieves differently and at his or her own pace.

All stages of the grief process are necessary. Denial may be very functional for a while. An apparent lack of concern may be a child's

way of coping with death. It is normal for a child to reenact the funeral in play and/or to pretend to be sick or dying in a play situation. Acting out feelings through play is a child's way of dealing with fears and emotions that he/she is not able to express verbally. If an unconcerned and unknowing attitude *continues* in a child, he or she should be encouraged to talk about their feelings and emotions. Do not be afraid of making children cry--tears can be a much needed safety valve.

Grief and anger can often lead to disruptive acting out behaviors. Many of these are normal and should be accepted with calmness. However, this does not mean that a grieving child should never be disciplined. The amount of energy expended to discipline a child while a parent is grieving is certain to be less than that required to correct a behavior problem that is allowed to develop for months or even years.

A grieving child needs permission and opportunity to grieve, someone to talk to, and reassurance of being loved. Gentle discipline is as important an aspect of that reassurance as hugs and kisses. Gentle discipline reinforces love and reassures a child that eventually everything will be all right again.

Children, like adults, need to express their pain and grief. Children need to be allowed to act out their feelings in ways that do not always seem appropriate to an adult; they may not be able to say what they feel with words, and must depend upon body language and behavior to vent their feelings.

A common emotion in grief is anger. Anger will come in several forms. It may be directed at their brother or sister who has died for deserting them or their parents. It may be directed toward those held responsible for the death, such as God, doctors, nurses, etc. It is best for a child and the others involved with the child to encourage expression of and discussion about these angry feelings.

Children want information about, and participation in the grief process. Parents should be told to allow them to ask questions, for it is part of their grieving process. They also need to be

straightforward and honest about the baby's death. Being evasive may cause problems later. Not knowing/understanding the real situation may prevent them from confronting and working through their feelings.

Most children over age six should attend the funeral unless they are *unwilling* to go; no child should be forced to do so. For children between the ages of three and six, personal judgment is needed. Rehearsing what will happen at the funeral is good preparation for the child. If the body is to be cremated or donated, these procedures will need to be explained to the child.

Children take death very personally: they often feel that they are either responsible for the death, or that they are being punished for some misdeed. Children are steeped in the theory that bad things happen to them when they are naughty, and younger children firmly believe in magic. An earlier hostility, even a dream or a wish that that person might die, can burden the child with terrible guilt and remorse.

Children often feel abandoned, that the deceased has run out on them, and may experience fears of further abandonment or an inability to trust others. This fear may lead to hostility toward those who are closest to them.

Youngsters from three to five may deny death as a regular and final process. To them death is like sleep; you are dead and then you are alive again . . . or like going on a journey; you are gone, then you come back again. Between the ages of five and nine, children appear to be able to accept the idea that a person has died, and that they will not return. But they may not accept death as something that must happen to everyone, particularly to themselves. Around the age of nine, children recognize death as an inevitable experience that will occur to them.

Children can be helped to an understanding of what has happened by honesty and reassurance. The effort to reassure a child by falsehood is doubly damaging because the child inevitably finds out

that he/she has been deceived, and then must not only deal with the deception but with their *deceiver*. He/she will no longer have a basis for trusting that person as a dependable source of information. A child's fears and fantasies are usually far worse when he or she is not told what has happened in a clear and precise way. Use correct medical terms. This helps the child understand the reality of the situation. Unhealthy explanations of death include "God taking someone away because He loved them" and "being in heaven." Children may begin to equate living to an old age as evidence of *not* being good, and may wonder why he/she should be good if God's reward is death. He/she may become angry with God, or may develop a fear of "being next to die" if they are good. Younger children may be "haunted" by fears of the person "watching them from above," or may simply not understand why the body stays in the ground if the person "goes to heaven."

Many parents, in trying to answer questions about death, tell children things they do not themselves believe because they simply can't think of anything else to say. If we as individuals and a society could ourselves come to terms with death, we could do a better job of telling our children about it.

The grief process is coming to a tentative end when there is the painful acceptance of the reality of the death, the reorganizing of life around the new circumstances, and the reestablishment of normal relationships and activities. However, at birthdays, holidays, and anniversaries of the death, grief is revisited. This is a normal and predictable part of the grieving process. These periods, over time, will become less and less painful for the child, and --while a sadness and loss remains--most of the pain will hopefully be replaced by cherished memories.



Talking to Children About Death

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Think about the age of your child. As with everything else, how your child views and reacts to the death of a family member is connected with their physical and emotional maturity. A three-year-old needs to be treated and spoken to differently than a teenager. Just remember that regardless of age, all members of your family will be affected by the baby's death.

Let your children tell you what they need. Listen to your child carefully, they will tell you what they need. Answer questions honestly, simply and as many times as they are asked. Children grieve differently than adults, so allow them to “play” out their emotions. Don't be surprised if you find your younger child in the corner replaying the death of the baby with friends or dolls, or an older child wanting to go out and play with their friends. These types of behaviors are common and do not mean that your child isn't feeling pain; it only means that the death is being handled in a manner that is comfortable for them.

Create an atmosphere where your child can express fears and emotions. Your child will be feeling many confusing emotions that are no different than your own. Unlike you, they do not have the emotional maturity or life experience to understand them.

Expect to hear expressions of anger, fear, and confusion. Never tell your child that they shouldn't be feeling a certain way. They are entitled to their feelings and most will pass with time.

Help them deal with their fears. Younger children don't think in the abstract, to them everything is concrete and real. If you tell them fairy tales about the death, like the baby went to sleep, or the angel of death took the baby, you may find that they become frightened that the same thing may happen to them. One of the biggest fears for preschool children is somehow they too will die and be separated from you, their parent. When explaining death use the correct words, such as, "Joey is dead. He won't be coming back." Even though your child doesn't quite understand what that means, they will start to understand that death is not reversible.

Reassure a child by sharing your feelings with them. Let them know that you too are sad about their brother/sister's death. Make sure they know that nothing they did or said or wished caused the baby to die. A child should be allowed but not forced to attend the funeral. Children also need to say good-bye. They can choose the most comfortable way to do so. You might suggest to the parent they ask their child/children if they would like to keep something of the baby's to remember their brother/sister.

Ask for help. If you find that you cannot talk to your child or are too distressed to deal with your child's emotions, speak to your minister, rabbi, or doctor. You can also call your local public health nurse or your local SIDS parent support group. Just remember that there are many people who are available to help you through this sad and difficult time.



Keepsakes and Memories

“We experienced a sudden, unexpected loss of our almost three month old son from SIDS. We were not anticipating ever being home without our baby. I’m thankful our family didn’t change or touch any of his belongings in our home. It was important for us to deal with our son’s belongings at our own pace.”

Jerry and Amber Thomas, In Loving Memory of ~Baby Gavin~

You only get one chance at creating such wonderful memories of the time with your baby. These keepsakes will become such treasured memories. There are many lovely ways and places that you can have keepsakes done and created in memory of your baby.

Keepsakes

Here are some wonderful keepsake and memory making ideas that parents have shared with us.

- Make a memorial garden
- Plant a tree and watch it grow
- Buy or make a memory box in which to place your baby’s keepsakes
- Set up a special display shelf or cabinet
- Have your baby’s photograph drawn as a pencil portrait
- Collect a Christmas decoration or ornament each year
- Have custom designed announcements made
- Purchase or make a memorial candle. You may like to light this on special occasions.
- Have your baby’s hand foot plaster casts done (the Emergency Department in many hospitals do this)
- You can purchase a photograph of the sunrise that was taken on your baby’s special day
- Collect and display your baby’s ultrasound pictures
- If your baby is eligible for a birth certificate you may like to have it framed

- Create a DVD slide show montage of your baby's photographs/videos
- Create a virtual online memorial website in your baby's memory
- Create a professionally printed memory book with your baby's photos and written story
- Adopt or name a star in your baby's memory
- Get a tattoo of your baby's name, hand, footprints, portrait or anything symbolic
- Collect the willow statues that have symbolic angels, mother child, parents, father and child

Coping with Special Dates

Coping with special dates can often be difficult. However, sometimes these dates can be a special day where you may do things in honor of your baby. Some special dates may include:

- Due date - the day your baby was meant to be born had your pregnancy been different
- Anniversary/birthday of the birth of your baby
- Anniversary of the death of your baby
- Christmas
- Mother's Day
- Father's Day
- Hanukah
- Halloween
- Significant dates of when your baby/babies would have gone off to school
- Significant milestone birthdays of when your baby would have turned 5, 16, 18, 21 etc.
- Other significant dates such as your birthday/partner's birthday/children's birthdays

Dates can create a sad feeling of what could have been or how your life would differ so much to the way you are feeling now. How you chose to get through these dates is entirely up to you.

Some Suggestions for What You Could Do on These Special Dates:

Balloon and Butterfly Releases

- You could release a balloon; write message on the balloon or choose a special type or color.
- You could arrange to release butterflies

Cemetery and Significant Places

- Visit the cemetery or special place you might like to take some flowers
- Spend time at the ocean or the beach
- Visit the hospital in which your baby was born
- Spend some time alone or together quietly...somewhere tranquil
- Do something nice for yourself where you can be alone with your memories

Celebration

- Have a special lunch or dinner with your partner or those close to you
- Celebrate with a party, you might also like to have a special cake
- Have a picnic
- Light a special candle on your own or with family and friends
- Buy a birthday card for your baby and place it in your memory box or at the cemetery
- Include your baby/babies in significant celebrations or family portraits/photographs (wear a photo badge of your baby)

Keepsakes and Memories

- Purchase something special or personalized in memory of your baby
- Buy a special piece of jewelry that represents your baby/babies
- Write a letter to your baby
- Plant a tree or make a memorial garden

- Name a star in memory of your baby

Make a Difference for another Bereaved Family

- Donate a bear in memory of your baby
- Donate a bereavement book to another family
- Make a donation in your baby's memory

We hope these suggestions will be a starting point for how to spend your day. Remember that you may choose to do many of the above or let the day pass without doing any. Both are okay...the most important thing is to get through the day.



"I like to buy a birthday cake for Jeremy on his birthday. It is still his birthday even if he isn't on earth to taste the cake. I know he is an angel in Heaven. I want to celebrate Jeremy's birthday because it is a concrete day to celebrate Jeremy's life. I certainly can't celebrate on his death day. I like to think that although if Jeremy had lived I don't know how we would be celebrating his birthday each year but I know I would have bought him a cake.

Peggy Kindler in loving memory of ~Jeremy Kindler~

"Birthday and anniversary are the same day. I like to be withdrawn and not so busy. I like to spend that day thinking of her, remembering her short life, and praying."

In memory of ~Samantha Ann Thompson Slizik~

Precious Daughter of Dana Ann and Rob Slizik, Sr.

Christmas Memorial Ideas

- Setting up a special Christmas display with your baby/babies' ornaments
- Buying a gift for another baby and giving to the Christmas tree gift funds of churches or charities
- Lighting a candle or your baby's candle on Christmas Eve or on Christmas day while everyone opens gifts
- Burn your candle during your Christmas lunch or dinner
- Decorate your baby's special place, whether it be at the cemetery or at home or another special place
- Include your baby's names or a stamp, cut out or initial symbolizing them on Christmas cards
- Write a Christmas card to your baby and keep it in their memory box
- Give family members and friends a gift in memory of your baby

Christmas Memorial Ideas

- Buying a personalized ornament to hang on the tree
- Getting a special decoration to display

We remember Rachel every year. At church there is an angel tree from which you can choose a tag to purchase a gift for a child, so we would purchase a gift to donate to a child the same age Rachel would have been. When Rachel's age exceeded the ages of the children on the tree, we started all over again. I think of those gifts as a present from Rachel to a little child.

Eileen M. Carlins in Honor of ~Rachel Ann~

There is a Special Angel
There is a special Angel in Heaven
that is part of me.

It is not where I wanted her
but where God wanted her to be.
She was here for just a moment
And though she is in Heaven
she isn't very far.

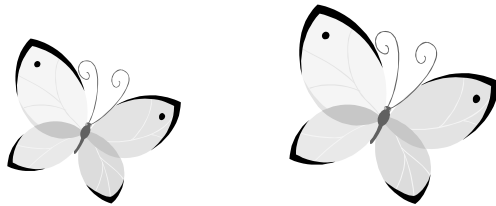
She touched the hearts of many
as only Angels can do.

She'll hold my heart forever
and I'll hold onto her heart too.

So, I send this special message
to the Heavens up above.

Please take care of my Angel
and send her all our love.

Kristy Achilles in memory of
~Jamela Tristian~



For Family and Friends

Do's and Don'ts

Compiled from thoughts shared by many families over the years and with permission, *The SIDS and Infant Loss Survival Guide*, *The Teddy Love Club™ Resource Pack*, and *The Compassionate Friends*

Feel Free to Say the Following:

- “I’m sorry.”
- “I can’t begin to imagine your pain.”
- “I feel so bad that you have to go through this.”
- “This must be extremely difficult for you.”
- “I want to do whatever I can to help you. What can I do?”
- “Talk for as long as you want. I have plenty of time to listen.”
- “You are good parents.” (Or say how wonderful the baby was.) Say anything you know to be true and good about the care they gave.

How to Help:

- Just be there for them, be a shoulder for them to cry on.
- Let them know you care.
- Tell them you don’t know what to say but you care.
- Be considerate: think about what you are saying, think about the comments you make.
- Offer help with practical matters...cooked meals, housework, watching other children, driving them somewhere.
- Ask them if there is anything you can do for them.
- Keep on asking them how they are, especially as time passes by.
- Refer to their baby by the name they gave him or her (if they chose to name their baby).
- Know they will not forget their baby.
- Some parents have said they would have loved to receive a birth card instead of a sympathy card.

- It may be a nice gesture to honor their baby by making a donation in their baby's honor.
- Do include your friend/family members' baby at significant celebrations, weddings etc. (Mention their baby in your speech/toast.)

“Our son, Matt, was 3 years old when our daughter, Rachel died. He was always aware of her presence in our family and a volunteer for the local SIDS group. When he got married, he and his bride, Jennifer, made certain the priest included Rachel in the prayers at their wedding to acknowledge her short, precious life. That meant the world to me.”

Eileen M. Carlins, in Memory of ~Rachel Ann~

What Not to Do and Say:

- Don't visit for too long unless you are close friends or doing something specific to help.
- Don't expect anything--from a cup of tea to your definition of “dignified” grieving.
- Don't be afraid of reminding the parents about the baby; they will never forget the baby and find it comforting to remember with someone.
- Don't avoid them because you don't know what to say.
- Don't make assumptions of how you think you would act or feel if it was you. You really don't know unless it happened to you.
- Even if you have experienced the loss of a baby, remember everyone's situation is different and unique; people deal with things in their own ways in their own time.
- Don't suggest that someone else's situation would be harder to bear.
- Don't be afraid to cry or even laugh. Both provide comfort in addition to giving the survivor permission to do the same.
- Don't expect them--and for goodness sakes do not admonish them--to “be strong.” If there is ever a time to allow oneself to be weak and needy, it is after the loss of

your baby. Survivors need to suffer through the pain to move through the grieving process, even though this is difficult for others to witness.

- Taking initiative is encouraged, but do not pack, move or even handle the baby's things unless asked to by both parents.
- If at first your offers to help or attempts at comforting are rejected, don't take it personally. Give survivors a few days, or even weeks, and try again.
- Don't wait until you have the perfect thing to say--there are no perfect or magic words. Say what is in your heart, or be silent.
- If you have lent the parents baby items or clothes, don't ask for them back unless it's absolutely necessary, and even then try to wait until they are offered.
- Don't blame anyone for the death--not the doctors or the babysitter or anyone. In a bereaved parent's mind, the possibility of blame opens the window to all of their personal self-doubts.
- Don't impose your religious views on them. Do not "sermonize or spiritualize." And, please NEVER call the loss "God's will" (even if that is your true opinion).

Do Not Give Pat Answers, Such As:

- "You'll be a better person because of this."
- "Calm seas do not a sailor make."
- "I understand." (Unless you, too, have lost a child.)
- "It was all for the best."
- "It will all work out for the best."
- "You're young. You can have other babies."
- "At least you have your other children."
- "These things happen."
- "I was praying for something to bring our family together."
- "Don't cry--be strong."
- "You can always try IVF."
- "It's good the baby wasn't older. You'd miss him more."
- "You should feel..."

- “Now you’ll have an angel in heaven.”
- “It was meant to be.”
- “You’re fortunate that you didn’t lose your whole family.”
- “Some people have it much worse than you. Just look at all the starving kids in...”
- “Maybe your baby would have been on drugs as a teenager, so it’s better that you avoided all that.”
- “Your baby is in a better place now.”
- “I know exactly how you feel. My dog died last year.”
- “You have to forget about this, put it behind you, and get on with your life.”
- “God picked you for this because He knew you were strong enough to take it.”
- “I don’t know how you can stand this. Why, if my child died, I’d die, too.”
- “God must have really loved you to have chosen you for this special burden.”
- “Well, that was a waste of nine months.”
- “At least you don’t have to pay for his college education.”
- “At least she died before you really got to love her.”

Please remember your family member or friend and their baby on special dates (due date, anniversary, birthday) and celebrations (Christmas, Mother’s Day, Father’s Day, Hanukah). Let them know that you are thinking of them and have not forgotten. This will mean more than you may ever know.

“Jeremy’s speech therapist asked me if there was anything she could do for me and I told her she could write something for Jeremy’s marker. I was too overwhelmed to come up with anything.”

Peggy Kindler, in Memory of ~Jeremy~

‘WE PLAYED, WE READ, YOU SANG ME SONGS,
OUR TIME WAS SHORT, OUR LOVE LONG’

Losing a Grandchild to SIDS

By C. Hosford, LCSW-C

By Permission of Center for Infant and Child Loss (Maryland)

The loss of a family member is painful, and the loss of an infant or young child is especially so. As a grandparent, you face a double blow--you have lost a much loved grandchild, and you are confronted with the pain of your own adult child.

The relationship between grandparent and grandchild is a very special one. Grandchildren represent the future, the carrying on of generations. Being a grandparent is different from being a parent of course, but once again you are involved with a new life, and all its attendant challenges and satisfactions. As with your own children, you have hopes and dreams for the future of your grandchild.

The sudden death of an infant means an abrupt severing of these fantasies and plans. The light goes out on all the images which now can never materialize.

Grandparents often feel helpless in the face of their own children's grief. Perhaps you were able to "make it stop hurting" when you children brought home the skinned knees and injured feelings of childhood and adolescence. Unfortunately, there is no way to stop the pain of bereavement.

This does not mean that you are not a valuable resource to your son or daughter. Bereaved parents often say that their own parents were primary sources of support--by listening, by being available, by sharing memories and feelings. Perhaps you could sit down with your son or daughter and talk together about the baby, about the death, about the feelings of guilt, anger and loss which are inevitable when an infant dies. Some people find it hard to talk this way, but it is probably easiest to deal with people with whom you have a long history of love and trust.

Grandparents come in a variety of ages, but it sometimes happens that the age of grand-parenting is also the time when one begins to face anticipated or real losses in life. An adult child may take a job

in another state or another country. Friends may begin to retire or move away. Possibilities for the future may become or seem to become more limited. At a time like this, the birth of a baby is a wonderful affirmation of life. The death of a baby, a devastating blow at any time, becomes even more so when it is experienced in the midst of other losses.

Your feelings of sadness and grief are very real. Some grandparents say, "But my daughter was the mother. She had the real loss." Remember that the baby was an extension of you, the object of your love, a hope for your tomorrow. In a SIDS death, everyone involved with the baby is affected by his/her death. Mourning experience may be different, depending on personality, history, circumstances, relationship to the infant, but they are all valid.

People are often surprised by how powerful [the feelings of grief] are. "It just pours out" a bereaved father said. "It's like a dam that breaks. It keeps coming and coming and you wonder, is this ever going to end?" Despite what people think, those feelings may not completely disappear. But that torrential flood of grief eventually forms a river and the river imperceptibly becomes a stream, and although that stream narrows, it could meander through your life forever.

Candy Lightner and Nancy Hathaway

Giving Sorrow Words

(With permission *The SIDS and Infant Death Survival Guide*.)

Just Say, “I’m Sorry”

By Gail Fasolo

By Permission of *The SIDS and Infant Loss Survival Guide*

You don’t know how I feel—please don’t tell me that you do.
There’s just one way to know—have you lost a child too?
“You’ll have another child”—must I hear this each day?
Can I get another mother, too, if mine should pass away?

Don’t say it was “God’s will”—that’s not the God I know.
Would God on purpose break my heart, then watch while my tears
flow?
“You have an angel in heaven—a precious child above.”
But, tell me, to whom here on earth shall I give this love?

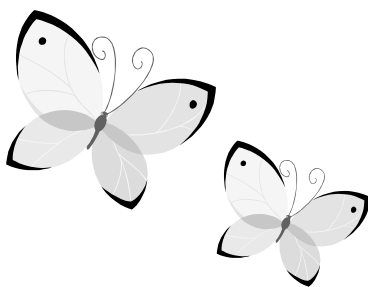
“Aren’t you better yet?” Is that what I heard you say?
No! A part of my heart aches—I’ll always feel some pain.
You think that silence is kind, but it hurts me even more.
I want to talk about my child who has gone through death’s door.

Don’t say these things to me, although you do mean well.
They do not take my pain away; I must go through the hell.
I will get better slow but sure—and it helps to have you near,
But a simple “I’m sorry you lost your child” is all I need to hear.



How to Make a Difference...

- Volunteer at Cribs for Kids® events, such as the Breath of Life Stroll each July in Pittsburgh.
- Create a local Breath of Life Stroll in your area to help raise funds.
- Distribute infant safe sleep brochures.
- Raise money to purchase portable cribs for families who do not have a safe sleep environment for their baby.
- Hold a “Cause” day at your place of work or school to raise funds.
- Become a United Way donor for Cribs for Kids®.
- Help to secure prizes and donations for the Breath of Life Stroll.
- Attend our fundraisers throughout the year to raise funds and create awareness.
- Reach out for support—and when you may be able—reach out and help others.
- Please share the mission of Cribs for Kids® and infant safe sleep with friends, family, and your community. The more awareness we create, the more families we can serve.
- Please contact us at anytime if you need a caring, listening ear or need support for a family member or friend who is bereaved.



Acknowledgments

We would like to thank the many parents, families and organizations who have generously shared their materials, thoughts and feelings to share with others who read this book.

For those of you who are beginning this grief journey, please remember that you are not alone—there are others who have been there before you and care very much. The following is dedicated to all families who reach out to help others.

The Bridge Builder

An old man going a lone highway
Came at the evening, cold and gray,
To a chasm, vast and deep and wide.
The old man crossed in the twilight dim
The sullen stream had no fear for him;
But he turned when safe on the other side,
And built a bridge to span the tide.

“Old man,” said a fellow pilgrim near,
“You are wasting your time with building here,
You never again will pass this way,
Your journey will end with the closing day.
You have crossed the chasm, deep and wide,
Why build you this bridge at evening tide?”

The builder lifted his old, gray head,
“Good friend, in the way that I’ve come,” he said
“There followeth after me today
A youth whose feet must pass this way.
This stream that has been as naught to me
To the fair-haired youth might a pitfall be.
He, too, must cross in the twilight dim,
Good friend, I am building this bridge for him.”