

A booklet for parents experiencing the loss of an infant

Empty Arms and Aching Hearts



LOMA LINDA UNIVERSITY

CHILDREN'S HOSPITAL



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The death of an infant comes as a numbing shock. After months of happy anticipation and joyous planning, you are suddenly faced with circumstances and adjustments that have to do with death rather than life. Immediately, difficult and painful decisions crowd for your attention, some of which must be resolved at once. Then as days lengthen into weeks and months, other problems arise to prolong the agony—problems between you and your spouse, your other children and friends. Probably the most difficult thing is facing your own internal response to grief, sometimes including the shaking of religious faith when God seems far away. The situation is made worse by the fact that you find yourself with little preparation and few guidelines to carry you through this tragic experience.

We have prepared this booklet to help you through the grieving process. Nothing that we write here will take away the pain and emptiness you are now feeling. But we hope the information here will help as you navigate this unfamiliar and unwelcome journey. Sharing grief with others who have suffered a similar loss can make the experience less frightening and give assurance that what you are dealing with is normal. Although you may feel lonely, please know that you are not alone.



Saying Goodbye



The first difficult questions each parent must answer come within the first hours after the loss. The answers to most of them cannot be delayed.

Should I hold my child? Should we name our child? Was our baby normal? Did I do something to cause the death? Why our baby? Should an autopsy be performed? What about funeral arrangements? Where can we turn for help?

Although the death of an infant is a terrible tragedy, your pain will lessen in time and you will want to remember this special child. A picture can be extremely valuable in providing validity to your child's existence as part of your life, even if it was only for a very short time.

We encourage you to see and hold your child. This is your special time to know, see, and say goodbye to your baby. Many parents are afraid at first, but most eventually are glad that they had the opportunity for this experience. In fact, many parents later regret not choosing to see their child. If you are unsure, ask the nurse or someone in the nursery to describe your baby to you.

Many parents who have suffered the loss of a baby have chosen to name their child. It can be helpful to name your baby no matter how small or how short a time he or she lived. Talk about your baby by name with family and friends. Again, this is a way of acknowledging the specialness of your child.

The Funeral or Memorial

A funeral or memorial is a way of formally recognizing a person's life. This is no less important for a baby than for any other person. The purpose of the service is to memorialize your baby and also to comfort you. It is another way of acknowledging your baby whom you loved dearly and who was a very special person to you. Funerals or memorials provide family and friends a way of expressing their concern and sympathy during your loss. It can also be an important step in the process of grieving. The hospital chaplain, social worker, or your own clergy can help you make arrangements which meet your needs and belief system.

Many parents question whether their other children should attend the baby's funeral or memorial. They may want to shield their young ones from the pain of death and sorrow. Yet it is acceptable for children to attend funerals if they so desire. The funeral provides children a way to say goodbye and show their love and grief for their brother or sister. Many children feel better if they can give some small gift—a drawing, flower, or small toy—to be buried with the baby. Parents can explain to the children that the funeral provides a time when friends and family can come together and express grief for the loved one that died. The child then will understand what is happening and not be frightened or feel isolated from the rest of the family.

Grief

We all feel grief at losing someone who is special to us. But the loss of a child is without doubt one of the deepest losses anyone can experience. There are many reasons for this; plans for the future included this child. The excitement of the new life you created and the desire to nurture this child have been interrupted and left unfulfilled. The physical and emotional hurt you feel is part of the process of grieving the loss of this very special someone—your baby.

Don't be afraid of the emotions or the physical symptoms you may be feeling. These do not mean that something is wrong with you. Nor does it mean something is wrong if you don't behave or feel the way others expect. We all need time to get over losing someone who is important. But each person handles grief in their own time.

During this period, friends and family may not understand how deep your hurt is. You as parents are the only ones who really knew your baby. Other people may soon forget; however, you continue to remember how much this child has been a part of your life—whether or not he or she ever lived.

Grief Responses

The moment you learn of your loss, you enter the grieving or mourning process. Some people believe that grief is a process that should be dealt with and then left behind. Research, however, has shown that grief may not be resolved for many months—or even years.

You will probably experience a host of emotions. Some of these emotions will be intense, while others will be barely discernable. At some point, you may think you have moved past a particular emotion, only to find yourself feeling that same way again.

You may find it easier to accept your responses and understand your reactions if you acknowledge these feelings. Grieving often includes these four dimensions:

1. Shock and numbness
2. Yearning and searching
3. Disorientation and disorganization
4. Resolution and reorganization



Shock and Numbness

In the beginning, you may be so stunned by this overwhelming experience that you act as though nothing has happened. You may have difficulty believing the news about your baby. Making decisions or even keeping up with the routine of your daily life may seem insurmountable. There are, however, many things that need to be done. Accept the offers of family and friends to help you get through this time of shock..

Yearning and Searching

This phase of grief usually follows the initial shock. You may feel anger about the unfairness of losing your baby. Questions may arise such as: “How could this have happened?” or “Why did this happen to me?” You may find it easy to take this anger out on those close to you: your spouse, family, and friends. You may blame God or the doctors and nurses who took care of you and your baby. Give yourself permission to express your sorrow. Tears are very healing.

Guilt about everything related to the death of a child is a frequent emotion. You may blame yourself for not having a normal child. Even with the assurance that there was nothing you could have done to prevent what happened, you may be convinced that something you did or something you failed to do caused the tragedy. Be assured that such a sense of guilt is perfectly normal, but it does not mean you are guilty.

With the tremendous sense of loss will come other painful feelings. You will find it difficult to concentrate and you may find little interest in things around you. As a mother, you may feel an emptiness highlighted by the fact that you are no longer pregnant. You may experience the physical discomforts related to hormonal changes at this time. Breast engorgement and perhaps even some leakage of milk may make this period very difficult. Perhaps you will feel a tightness in your throat, choking, and shortness of breath. You may experience a feeling of emptiness and exhaustion.

Another possible reaction is fear that you are losing your mind. You feel as though you cannot concentrate on anything but your baby. You may even feel at times that the baby is present. Some parents find comfort by carrying a photo, an article of clothing or one of the baby’s toys with them. Researchers say this type of behavior is normal while grieving because parents are concentrating on separating reality from their dreams. In fact, having mementos may help you grieve your baby.

This stage of yearning and searching may last as long as four months and will very likely return on the anniversary of your baby’s birth and death, or during special family occasions and holidays.

Disorientation and Disorganization

The realization of your loss now becomes acutely painful. As a result, you neglect or forget such basic activities as eating and sleeping because of the heightened awareness that all your excitement and plans have ended in disappointment. You may feel very lonely and isolated in your sorrow. This is the time to contact those around you who are concerned and able to give you support.

Another problem is dread of being alone and an almost overwhelming sense of danger. Fear for the safety of your other children and at the same time, a fear of caring for them, can distress you.

During this time you may find it difficult to start or continue routine projects. To associate with mothers of healthy babies and to see pregnant women may prove unbearable.

Physical problems may occur, such as migraine headaches or ulcers. Sedatives and tranquilizers should be used with caution, for they may make coping even more difficult by giving you a false sense of security which can keep you from working through the grieving process.

Often when people are grieving, they lose appetite. Food may seem tasteless, or hard to swallow. Appetite loss can contribute to further depression. The following suggestions may be helpful:

1. You'll find comfort in maintaining normal routines of sitting down for meals even if you don't eat much.
2. Your friends can be helpful in preparing food for your family.
3. During this time, it is best to avoid foods high in sugar since they can contribute to mood swings.
4. Eat with a friend who is a good listener. This can provide a time to share feelings.

Sleeplessness is another problem experienced by people who are grieving. This may be helped by exercise, such as taking a brisk walk. Taking a warm bath before bedtime or listening to soft music can further relax you.

Resolution and Reorganization

Eventually you will notice your level of energy increasing and your ability to make decisions returning. This does not mean that you will never again feel the sadness. It does mean that you have freed yourself from the strong pain associated with your baby's loss. You are prepared to move forward without the persistent questions and concerns you previously experienced. This period is easier if you have had others encouraging and supporting you. It is hastened for those who accept and express their grief rather than deny it. Don't try to suppress your feelings; they are very normal.

This experience will change you in many ways. In time, you will be able to relate to others in a deeper, more meaningful way than before.

Relationships

Father and Mother

When a baby dies, fathers and mothers find themselves in a crisis situation unlike any other they have faced before. This may be their first encounter with the death of a loved one or with a real crisis. The manner in which they deal with the problems can have a lasting effect upon their relationship.

The death of a baby can cause serious stress in a marriage. Contrary to what some might expect, common grief does not necessarily draw a couple closer. Grief is a pain that mates cannot shield each other from nor bear for each other. This discovery can shatter a couple if each one expects to lean on the other as they mourn. They find that one cannot lean on someone who is already bent with sorrow. As a result, parents may feel isolated from each other.

Although every couple has a unique experience, one of the major problems that most grieving fathers and mothers have in common is impaired communication. Although it may be very difficult, keep talking to each other. Your experiences of grief will be different and that is okay. Communicating offers an opportunity to understand each other better.

Other problems may arise from the fact that each parent has become attached to the baby at different stages and intensities during the pregnancy. For mother, this bonding usually begins quite early. She has felt the baby within her body and has accepted it as an extension of herself. For father, this attachment may be more intellectual in the beginning, so by the time movement is felt, he has a great deal of emotional “catching up” to do.

Mother may feel a great sense of loss while father may experience only disappointment. Because each parent is not at the same point in their grief, each may feel misunderstood by the partner. This can lead to feelings of bitterness and resentment within the relationship.

In addition, society has differing expectations of grief responses appropriate for men and women. It is acceptable for women to have a great outpouring of emotions whereas men are generally expected to remain strong and protective. This places father in a position where he is unable to express his real feelings. A father then may suppress his grief. Others often fail to realize that father needs support and understanding too. Mother may see his lack of emotional display as a lack of concern for the loss. Walls can soon develop, and communication breaks down.



These differing roles and expectations can influence the reactions of both father and mother after the stressful experience of their loss. Parents aware of these differences can avoid pitfalls that may be damaging to their relationship.

Your Other Children

All of the family is affected by a birth tragedy. At a time when parents are struggling to deal with their own feelings, it is even harder to respond to the emotional needs of other children, helping them to work through their feelings. Children may experience confusion about what happened, feel guilty, believe that they might have caused the baby's death, feel isolated from their grieving parents, and have fears for their own lives and security. They, like their parents, are bereaved, and they may be saddened, disappointed, or angry because they don't have the baby they expected.



Children experience many of the same grief feelings that their parents do. Much of their anxiety can be alleviated, however. The parents' ability to cope with their own feelings of grief, loss, anger, and disappointment helps their children to handle these same feelings within themselves. An openness with grief lets the children know that they did not cause the irritability and depression in their parents, but rather that these are a natural result of grief. The parents' example in facing grief can show the children that it is all right to cry, to be sad, to be angry—even to laugh and forget at times.

Understanding a Child's Development

Be aware of each child's level of understanding or misunderstanding about death. Very young children, ages two and under, have the concept of "here" and "not here." Preschoolers, three to five years old, see death as temporary. Children six to ten years old understand the reality of death and are curious about biological aspects of death and details of burial. From age eleven onward, a child conceives of death in a manner similar to that of an adult.

It helps to explain truthfully to children, on their level, what caused the baby's death. All their questions should be answered simply and directly. Even very young children can understand the explanation, "His little body couldn't work any more." The more children understand, the less fearful they will be.

Euphemisms should be avoided, for they are easily misunderstood by children. Phrases such as “we lost our baby” may be confusing to a young child, since young children interpret literally what they hear. Also, the cause of death should not be attributed to God. The baby was not taken because God wanted him in heaven; rather he died because his body could not work anymore. Comments about God wanting the baby may cause children to be afraid of God and fear that they too may be wanted in heaven. This can lead to sleep disturbances and behavioral problems.

It is essential that both younger and older children express their feelings, fears, and questions. Since parents are deeply affected by this tragedy, other children in the family cannot be shielded from it. Parents who find ways to cope well with their own grief are providing the best possible atmosphere for their children to eventually accept and grow from the experience. Most important are the love and security parents provide and the openness to deal with the feelings expressed.

Common Emotions

Loss and sadness may be the child’s simplest feeling about what has happened. Connected with this can be the fear of separation from their parents.

The distinction between fantasy and reality is less clear for children than for adults, particularly young children. Some children may feel guilty about the death, thinking that their anger or jealousy felt toward the baby figured prominently in the baby’s death. It is important to reassure them that negative feelings between brothers and sisters are common and that wishing something to happen does not cause it to happen.

When a loved one dies we are confronted with our own mortality, and this is true for children also. Their misconceptions can make death a constant threat to them. In responding to this concern, it is important to acknowledge the reality of the fear itself and to make it plain that their immediate death is highly unlikely.

Another serious question for the surviving children is whether their needs will continue to be met. Parents, because of their own grief, may be temporarily unable to provide adequate love and attention. This can be alarming for the surviving children. They may be frightened or puzzled by parental emotions of an intensity they have not seen before. Seeing their parents, whom they view as pillars of strength, overwhelmed and shaken by death, threatens the security and orderliness of their world. It is helpful to reassure the children that the depth of their parents’ grief does not lessen their love felt for them.

Children may be angry at the baby for dying, angry at doctors or parents who were unable to save the baby, or angry at friends who still have babies in their families. It is helpful for the children to be able to talk about their hopes, disappointments, and anger. This will not only alleviate their guilt at feeling angry, but will also teach them that it is acceptable to express that anger.

During this time children may temporarily regress emotionally and developmentally and display tantrums, dependency, loss of manual skills, impaired learning ability, and aggressive behavior. Parents need to be patient and loving during this time and recognize that their children may need more physical touch and holding.

Friends

After the death of an infant, parents often feel a type of alienation or abandonment by friends and family. Bereaved parents may come in contact with people who fail to provide them the support they need. They should realize that this failure has various causes. It is difficult for others to grieve the death of a child they have never known. Many people are ill-equipped to deal adequately with the situation. Their sense of inadequacy can lead them to numerous excuses for not calling a bereaved parent. Many feel awkward in not knowing what to say.

However, it is important for you to share your experience with empathetic listeners. At the beginning, you may not feel like talking. As the reality of the loss sinks in, mothers and fathers may experience an intense need to talk. You may find, though, that others now are ready to forget. When you want to talk, it may be that there is no one to listen. It is difficult for others to understand the depth of your feelings, and often they may unconsciously withdraw support when you need it most. Here is when support groups, a close friend, a counselor, or your clergy may be helpful in providing a place for you to openly express your feelings.

Although it may seem unfair, the responsibility for sustaining relationships rests with the bereaved parents. Parents have to take the initiative and call their friends and family. Open the doors of communication. People want to help and comfort you; they just need to be shown how.

It is not a sign of weakness on your part to admit that you need help and comfort. Contact your friends and family, ask how others are doing. Parents can put people at ease by speaking freely. Let your friends and family know your needs by telling them. If you want to talk about your baby, then say so. If you sometimes cry while discussing your baby, yet find it healing, let others know that. They may want to cry with you. But don't pretend that everything is fine if it really isn't.

Shadow Grief

The death of an infant is never truly forgotten by those who have experienced it. As parents, you will bear the heartache alone long after others have forgotten. "Shadow grief", a dull ache buried deep within you that surfaces under certain circumstances, may remain with you for the rest of your life. It has a tendency to recur on special occasions, such as your baby's birthday or day of death. Its intensity can vary from person to person, from mild feelings of sadness to tears.

One way of coping with shadow grief is to recognize its existence. It may always be there regardless of your best efforts to dispel it. It may be helpful to do something special on the anniversary of your child's death. It is a way of remembering your baby.



Living with Grief

A helpful way to work through grief is to be with others who are facing a similar loss. Most communities have support groups that offer a place to share your grief journey. Each October, across the nation, organizations host *A Walk to Remember* where families can join together to honor their babies. It is important that you find a community that can support you through this time.

Your spiritual outlook will affect the way you face your loss. Many parents have found that their spiritual faith has helped them find strength, support and comfort. Many have found it helpful to allow their church community to share their grief. Spiritual faith can give you the assurance of God's love and support. You may feel at times unable to bear your grief, but faith can give you the strength and hope to believe that healing will come... in time.

The memories of your baby will always be part of your life. That is not to say you will always feel the way you do right now. The journey of grief is unique for each person, but you will find yourself moving along the path toward a new normal. You will always have a very special place in your heart for your baby, but you will find room there for your other loved ones as well. Until you find that place, be gentle on yourself; give yourself space to grieve in the way that you need and surround yourself with people who are willing to support you in that process.

A close-up photograph of a white lily flower with prominent stamens, resting on the spine of a black leather-bound Bible. The Bible's spine has the words "HOLY BIBLE" embossed in gold. The background is softly blurred, showing a white cloth and a white tissue.

May you feel God's presence during this time of sadness. In the midst of life's greatest pain, God reminds us that He is with us – always. Today, in your sorrow, may you find comfort in the promise, "Weeping may endure for a night, but joy comes in the morning."

–Psalm 30:5

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