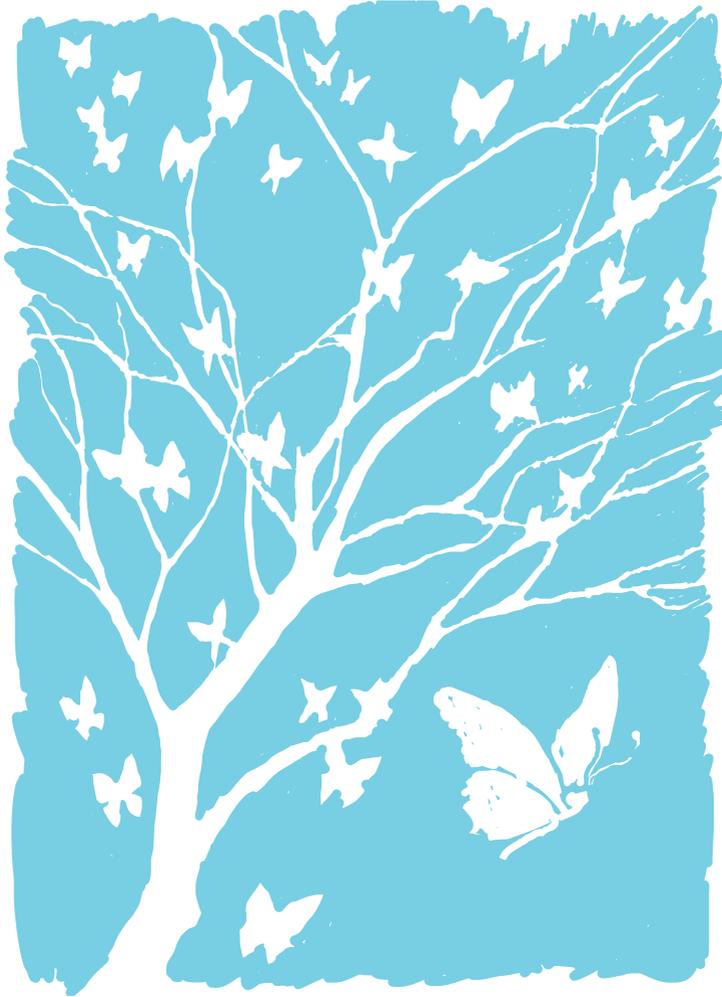


Shattered Dreams



LOMA LINDA UNIVERSITY
CHILDREN'S HOSPITAL

A book for parents experiencing the loss of a child

Shattered Dreams



LOMA LINDA UNIVERSITY

CHILDREN'S HOSPITAL



Shattered Dreams

The death of a child is one of the deepest losses one can experience. The numbing shock disrupts plans and shatters dreams. Your plans for the future included this child. The thrill of watching your child grow and develop disappears, and the desire to nurture and protect your child is left unfulfilled.

Immediately you are forced to make difficult and painful decisions that require energy that you do not have. You are faced with the changes that take place in your other relationships: changes between father and mother, parents and children, family and friends. Probably the most difficult aspect is facing your own internal, unshareable grief. You will likely have many fears and questions: How do we make these decisions? What will we do now? Will this anguish ever end? Where is God? No doubt you feel overwhelmed, alone and unprepared to handle this experience.

In order to help you cope with the distress and despair of your grief, we have prepared this book for you. 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. We have discovered that sharing grief with others who have suffered a similar loss can make the experience less frightening and give assurance that the emotions you are experiencing are 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 an autopsy be performed? What about funeral arrangements? Where can we turn for help?

We encourage you to see and hold your child. This is your special time to know, see and say goodbye. 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.

The Funeral or Memorial

A funeral or a special service to memorialize your child and to comfort you are ways of acknowledging how dearly loved and special your child was. Such services can also provide family and friends with a way of expressing their concern and sympathy during this time of loss.

These can be important steps in the grief process. The funeral or memorial can be anything from the traditional funeral, to your child's expressed wishes before death, to a service spontaneously created in loving memory of your child. It can be a way of expressing gratitude for friendships. It can be a time of remembering. The mortician, hospital chaplain, social worker or your own clergy can help you make arrangements to meet your needs and belief system.

Many parents question whether their other children should attend a funeral or memorial for a brother or sister. Some have a tendency to try to shield their children from the pain of death and sorrow, but since parents are deeply affected by this tragedy, the other children cannot be protected fully from it. In fact, many believe that it is helpful for children to attend funerals, if they so desire. The child's wishes need to be listened to carefully. Children not involved in some way in the family sorrow may feel rejected or assume that their presence does not provide their parents with comfort. Children will eventually increase their self-confidence and a sense of mastery over loss when they share the grief with the parents. This involvement also begins the process in which surviving children and parents begin to rebuild and strengthen their relationships.

The funeral can provide a time for children 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, a flower or a special toy) to be buried with their brother or sister. Parents can explain to the children that the funeral provides a time when family and friends can come together and express grief for the loved one that died. The children then will understand what is happening and not be frightened or isolated from the rest of the family. If the child has not chosen to attend the funeral, a very supportive situation should be created for the child in which he or she can say a personal goodbye.

A woman who was four years old when her brother died still remembers, years later, how she felt about not being allowed to attend the funeral: "He was my brother and I should have been there. I felt left out and confused. As I grew older I became angry that I had not been given the chance to say goodbye to him. Recently I had my own ceremony at the gravesite. I feel as if I have finally said goodbye."

Grief

The physical and emotional pain you feel is part of the process of grieving over the loss of this very special person, your child.

Don't be afraid of the emotions or the physical symptoms you may be experiencing. These feelings do not mean that something is wrong with you. Nor does it mean something is wrong if you don't behave or feel a certain way at a certain time. We all need time to grieve. Because each person is an individual, each one handles grief in his or her own way and time.

During this time of grief, friends and family may not understand how deep your hurt is. As a parent, you are the one who knew your child's favorite foods, toys, dreams and fears. Other people may forget; however, you continue to remember, for this child will always be part of your life.

Responses to Grief

The moment you learn of your child's death, you enter the grieving or mourning process. You will probably experience a variety of emotions over a period of time and in no particular order. Some of these emotions you may feel with great intensity, others not as strong. Perhaps you think you have moved past experiencing a particular emotion, only to find yourself feeling that same way again.

You may find it easier to accept your responses and understand the grieving process if you can identify these feelings. Such grieving responses include 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 child. Making decisions or even keeping up with the routine of your daily life may seem impossible.

Many parents feel a need to confirm this loss by seeing and touching their child. We suggest that both parents see, touch and hold their child.

Yearning and Searching

This phase generally follows the initial shock. You may feel anger about the unfairness of your child's death. Questions may come to mind, such as "How could this have happened?" or "Why did this happen to me?" You may find yourself taking this anger out on those very close to you: your spouse, family and friends. You may blame God or the doctors and nurses who cared for your child. You may even feel anger towards your child for leaving you. Give yourself permission to express your feelings. Safe expression of anger provides a release and can help avoid extreme or prolonged depression.

Guilt about everything related to the death of a child is a frequent emotion. Even with assurance that there was nothing you could have done to prevent what happened, you may be convinced that something you did, something you failed to do or something you could have done differently caused this tragedy. Over and over again you may say to yourself, "If only ____." Take this opportunity to change the thoughts of guilt to thoughts of regret. This will help to remove the responsibility that does not necessarily belong to you.

Other painful feelings may come with this tremendous sense of loss. You may find it difficult to concentrate or you may also find that you have little interest in things around you. Perhaps you will feel a tightness in your throat, a choking feeling and even shortness of breath. You may feel empty and exhausted.

Another painful reaction is the fear that you are losing your mind. You may feel as though you cannot concentrate on anything but your child's death. You may even feel at times that your child is present, that you see his image or hear her voice or footsteps. Some parents find comfort by carrying a photo, an article of clothing or one of the child's toys with them. This can all be frightening. But remember that these are normal reactions to your loss. Other parents have expressed similar feelings.

Susie, the mother of a three-year-old who drowned shared this: "I sit in her room a lot; sometimes for hours. Her hand print is still on the window. I don't ever intend to wash it off. I go through her clothes and smell them. I rub them all over my face. There are some days I do nothing else but sit in her room."

At some point in your grieving process, you may feel a need for structured support. Most people find a support group is just what they need while others find that individual therapy is helpful.

Disorientation and Disorganization

During this time, the realization of your loss becomes acutely painful. You may begin to experience increased fears and anxieties, such as an overwhelming sense of danger and the dread of being alone.

Exaggerated fears for the safety of your other children may disturb you, and yet at the same time, fear to care for them may also distress you. Although you may feel frightened and isolated, this is the time to contact those around you who are concerned and able to give support.

You may also find it difficult to concentrate or may have problems starting or continuing routine projects. Seeing other families with children or seeing things related to children may be almost unbearable at times.

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

Often, when people are grieving, they don't feel like preparing or eating food. Food may seem dry and tasteless and be hard to swallow. This loss of appetite can contribute to further depression. The following suggestions may be helpful:

1. Try liquid meals, such as instant breakfast drinks, fruit smoothies or juices.
2. Maintain normal routines of sitting down for meals, even if you don't eat much.
3. Ask a friend to help in preparing food for your family.
4. Avoid foods high in sugar, since they can contribute to mood swings.
5. Eat with a friend who is a good listener. This can provide a time to share feelings.

In contrast, other parents may find they increase the amount of food they eat during this time. If this is a problem, regular, light exercise may be helpful.

Sleeplessness is another problem experienced by people who are grieving. This may also be helped by exercise, such as taking a brisk walk. Taking a warm bath or shower 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 pain of your loss. It does mean that the strong, overpowering pain associated with your child's loss has decreased. You are prepared to move forward without the persistent questions and concerns you previously experienced.

One mother remembers feeling this: "One morning I woke up and heard a bird singing outside my window. It was just a little thing, but it had been a long time since I had noticed anything beyond my grief. I knew then I was on the road to recovering. When I remember Jason, I still am deeply saddened. But now I have happiness in my life and many good days. It didn't come all at once and there are still times of sadness. But I'm getting better."

This period is easier if you have allowed others to encourage and support you. It comes more quickly to those who accept and express their grief rather than deny it. This experience of resolution and reorganization will change you in many ways. For one, you will later be able to relate to others in a deeper, more meaningful way than before.





Relationships

Father and Mother

When a child dies, parents find themselves in a crisis situation unlike any other they have ever faced. This may be their first encounter with a significant loss. The way these stresses are dealt with can have a lasting effect on relationships.

During this time it is important to look at one's usual style of coping with a crisis. The coping style will not likely change during loss or crisis, but may become exaggerated. For example, if one parent copes by being silent, there will be no radical change during grief. In fact, he or she may become more silent and withdrawn during crisis.

One parent may feel like this: "I just wish she would stop trying to make me talk. I miss Heather so badly and I feel so much pain inside, but I just can't talk about it. I know she really wants me to talk to her, but I can't."

Similarly, if one parent copes best through verbalizing, this need to give expression may be even stronger.

Some think that a child's death brings a couple closer together. However, the opposite can occur. The shared loss does not necessarily draw a couple closer. Many bereaved couples have difficulty relating to each other after the death of their child. They may be put into a position in which each must bear the pain alone. Grief is a pain that parents cannot protect 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. As a result, parents may feel isolated and alone in their grief.

One father expressed these feelings, "It put a real strain on our relationship. We had always shared experiences and done things together. I spent long hours at work. I used any excuse to stay away and escape my grief. Coming home only brought my pain to the surface."

A couple's relationship can also be affected by the way society expects men and women to express grief. It is sometimes assumed that women will be more demonstrative in their emotions. Men, on the other hand, are often expected to remain strong and suffer in silence. This may place a father in a position where he is unable to express his feelings easily. Others often fail to realize that fathers need support and understanding too. Fathers feel sadness, and it is important for them to communicate these feelings.

One father put it this way, "I have to be strong. Everyone encouraged me to be composed around Cindy. I was told not to show any emotion because that would only upset her. But I was hurting too."

Although every couple's experience is unique, one of the major problems that many grieving parents have in common is difficulty talking openly to each other. The communication gap widens while feelings and resentments become stronger. Former areas of disagreement and conflict may come up again, sometimes with greater intensity. Feelings of guilt, anger, sadness, and disappointment over their child's death may be projected onto the other partner. Partners may blame each other for something they were both powerless to prevent.

"I thought we knew each other so well. Often it seemed that we could just read each other's mind; we didn't have to say anything to each other. After our son's death, our silence was too loud; our talk said nothing."

There may be times when one partner needs to talk and the other feels that talking is too painful. Any attempt to share feelings or bring up the subject may be met with anger and an unwillingness to listen. However, it is important to be with each other in a way in which grief can be shared. Even though each may deal with grief in a different way, it is important for each to try to understand the other's needs. This may take some effort and patience, for honest, personal expression of pain can be difficult.

There are some positive things parents can do during this time to help their own relationship survive and avoid some of the communication problems:

1. Recognize the strengths in their relationship and the things that attracted them to each other in the first place.
2. Spend time together remembering their child, even if it is just looking at photos or sharing a dish of the child's favorite ice cream.
3. Spend time together doing something they both enjoy.
4. Respect each other's personal reaction to the grief process.
5. Be gentle and caring with each other.
6. Know that it is all right to seek outside help during this time (e.g., support group, counselor, clergy).

Parents should remember that there is no one else in the world who can better understand the tragic loss of their child than they. It is something they both share, though in different ways. A couple that is 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 child's death. At a time when parents are struggling to deal with their own feelings, it is even harder to respond to the emotional needs of their children, helping them to work through their feelings. Children may experience confusion about what happened, feel guilty or believe that they might have caused their brother's or sister's death. They, like their parents, are bereaved, and may be saddened, disappointed or angry because they no longer have the same family they had before.

The parents' ability to cope with their own feelings of grief, loss, anger and disappointment helps their children to cope with these same feelings. This is a time to be alert to any cues the children may give that indicate a need for sharing with parents. An open expression of feelings lets children know that these are natural results of grief. A parent's 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 sensitive to each child's level of understanding or misunderstanding about death. Very young children, ages two and under, have the idea of "here" and "not here." Preschoolers, three to five years old, see death as temporary. Children six to ten years old better understand the reality of death but are curious about physical aspects of death and details of burial, an interest which may lead to bizarre fantasies or fears. From age eleven onward, a child views death in a similar manner to that of an adult.

It helps to be truthful in explaining to children, on their level of understanding, what caused their brother's or sister's death. Even very young children can understand the explanation, "His body couldn't work anymore." A child needs to know that a dead person doesn't breathe, sleep, need food or feel pain. All their questions should be answered simply and directly. Parents' own beliefs will determine what they say about the meaning of death and about life after death. The more children understand, the less fearful they will be.

Euphemisms or attempts to "gloss over" the facts should be avoided. These are easily misunderstood by children. Young children interpret literally what they are told. Phrases such as "we lost your sister" or "she went to sleep" may lead to fears of getting lost or going to sleep and may cause nightmares. Also, the death should not be blamed on God. Phrases such as "God took her" may lead to hatred of God for being cruel. Comments about God "wanting" the child may cause surviving children to be afraid of God and fear that they, too, may be wanted in heaven.

This is illustrated by an account cited by Dr. Roberta Time in *Living With an Empty Chair*: “At age three or four while shopping with my mother I overheard a conversation with a neighbor – ‘It’s a shame she lost her mother; she was so young.’ I envisioned a girl my age walking out of a store, and noticing her mother wasn’t following, and not being able to find her ... For years I couldn’t understand why the girl had stopped looking for her mother, and how it was possible for them to never find each other.

It is essential that both younger and older children be allowed to express their feelings, fears and questions. Since parents are deeply affected by this tragedy, children in the family cannot be shielded from it. A child’s grief will depend on his age, previous death experience, what the family will allow and the child’s own way of relating to the world. Each of the surviving children will grieve differently. Parents who find ways of honestly and openly expressing their own grief are providing the best possible atmosphere for their children to eventually accept and grow from this experience.”

Common Emotions

The fear of loss and separation can be a child’s biggest fear. Connected with this can be the fear of separation from their parents. This may be a time when children feel abandoned and confused because their familiar position within the family has been changed. Reassurance, predictable routines and making small promises that can be kept will help to lessen this fear.



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 the anger or jealousy they felt toward their sibling caused their death. Most children have some feelings of guilt, but will have a difficult time expressing them. 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.

The brother of a boy who died of cancer remembers this: “I used to have nightmares that Scott died because I hit him. It took me years to understand I had nothing to do with his death.”

When a loved one dies, all children as well as adults are confronted with their own mortality. Children’s misconceptions can make death a constant fear. It is important to acknowledge the reality of this fear and to make it clear 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, who may be frightened or confused by parental emotions of an intensity they have not witnessed 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 the love they feel for them.

Children may be angry at their sibling for dying, angry at the doctors or parents who were unable to save their brother or sister or angry at friends who still have a complete family. It is helpful for the children to be able to talk about their anger, disappointments and hopes. Not only will this help decrease their guilt for feeling angry, but also will teach them that it is acceptable to express their anger.

During this time, children may temporarily regress emotionally and developmentally. They may display tantrums, dependency, loss of manual skills, impaired learning ability or aggressive behavior. Parents need to be patient and loving during this time and recognize that their children may need to be comforted and held more often. If the children are in school, parents would be wise to communicate with their child's teacher to collaborate in supporting the child.

Friends

After the death of a child, parents need support and sympathy. They often, however, feel alienated and abandoned by friends and family. Bereaved parents may come in contact with people who fail to provide them the support they need. Many people are not prepared to deal with death. Their feelings of inadequacy can lead to many excuses for not calling a bereaved parent. Friends do not know what to say or fear they'll say the wrong thing. They don't know how to take the first step toward grieving parents and may wonder how close they should come. Fortunately, some friends will be able to relate as usual, but others may never be heard from again.

One young mother whose daughter died in an accident shared this: "I felt as though everyone was walking on eggshells around me. Friends with young children avoided me like I had the plague. When I needed comfort and support most, I felt alone and abandoned by my friends."

It is important for you to share your story with an understanding listener. Sharing your loss helps to confirm your experience. At first, you may not feel like talking. As the reality of the loss sinks in, mothers and fathers often experience a strong need to talk but find that others are trying to forget, and 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.

When this happens, support groups, a close friend, a counselor or your pastor may be helpful in providing a place for you to express feelings openly.

Although it seems unfair, the responsibility for staying in touch may rest with the bereaved parents. Open the doors of communication. Take the initiative and make the first call. You can put other people at ease by speaking freely. People want to help and comfort you; they just need to be shown how. It is not a sign of weakness to admit you need help and comfort. Be honest with your family and friends and tell them what you need. If you want to talk about your child, then say so. If you sometimes cry while discussing your child, yet find it healing, let others know that. They may want to cry with you. But don't pretend that everything is fine when it really isn't.

Special Memories

The death of a child is a difficult loss for the entire family. You may wonder if it is possible to live without your child. As you work through your grief, you will begin to find comfort in the memories of your child. Many reminders may keep your child's memory close to your heart. Photographs and portraits, along with clothing and small treasures, are concrete ways of remembering. They are real and can be touched and held. Memories can be shared with others through stories and recollections of special days and events. Your child can also be remembered in silence and solitude. Your child is always part of your memory and will never be forgotten. In time, happy and sad memories will blend in a unique kind of balance. Parents come to cherish memories, knowing and feeling that their child is always a part of them.

A mother recalls the death of her daughter: "It has been years since she died, although sometimes it seems like yesterday. Certain things will remind me of her, like at the mall when I pass her favorite ice cream store or see a toy she would have liked. I feel sad sometimes, but mostly remember her with love and happiness."

Shadow Grief

The death of a child is never forgotten by those who have experienced it. As parents, you will bear the heartache 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 lives. It has a tendency to recur on special occasions, such as your child's birthday or anniversary of their 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. Some parents find it helpful to do something special on the anniversary of their child's death. It is a way of remembering your child.



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. 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 child 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 child, 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" printed in gold. The background is a soft, out-of-focus white surface.

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

Shattered Dreams is made available through

Loma Linda University Children's Hospital
Nursing Bereavement Programs

Compiled by

Carla Gober, MPH, RN
Heather McEachren, BSN, RN
Brenda Collins, RN, MS
Donna Stephan, BSN, RN

Special acknowledgement to

Lynn and Dennis Doyle and members from Circle of Hearts

Special appreciation to

Linda Johnson, PhD, RN

Additional copies may be ordered from:

Loma Linda University Children's Hospital
Nursing Bereavement Programs

11234 Anderson Street, MC 4011, Loma Linda, CA 92354
909-558-7261

