



# Dear Parents,

You have just received devastating news: your precious baby has died or will soon die. With other life-changing events, you usually have some time to plan and prepare for what is about to happen. Unfortunately, this is not so with the death of a baby. If your baby was born very early or very ill, you may not have had time to parent your baby as you had planned. If your baby died before birth, you have had no time to do this at all. You may be feeling numb or in a state of disbelief.

As bereaved parents, we have learned how important it is for you to take time now to parent your baby. Creating memories will help your passage through grief and aid in your healing. The options offered may seem overwhelming. You will have difficult decisions to make. The staff will gently lead you.

The next hours are for you and your baby. Do not let anyone rush you through this time of saying hello. We never hear families say they have spent too much time with their baby or created too many memories. We have only heard regrets. Remember, this is the only time you will have. If this become too intense or overwhelming, you can take a break and return later. No one wants you to feel rushed in any way. You will know when it is time to say goodbye.

Some parents understandably feel like they want to run from the hospital after hearing such terrible news. Even if you plan to view the baby in the funeral home, take as much time as you need now. Please know that the staff is not afraid of your tears or your mourning. They may shed a few tears with you. Nothing is as sad as losing a baby.

We cannot take away your pain, but we can help you in your memory-making experience. We understand that where there is love, there is pain.

Sincerely,

Dave & Melissa Barry, Founders of the Forget Me Not Foundation

www.fmnfoundation.com

#### TABLE OF CONTENTS

Making Memories to Last a Lifetime	3
Planning a Precious Goodbye	3
The Journey of Grief	4-8
Fathers Grieve, Too	9
Intimacy & Sex	10
Helpful Information for Family, Friend & Employers	11-13
Resources	14-16

# Making Memories to Last a Lifetime

## Suggestions for Parenting your Baby and Creating Memories

#### At the Hospital

- Call your baby by name
- A Hold your baby for as long as you want
- f you feel you haven't spent enough time with your baby, ask the nurse to bring the baby back to you, even the following day
- Unwrap your baby and examine his or her every feature
- As Mom and Dad, spend private time with your baby.
- Invite your family members to come and visit, including siblings
- f possible, bathe your baby, comb your baby's hair, and ask for a lock of hair
- Allow the staff to help you create memories such as pictures, footprints, and handprints
- f desired, have family or staff contact a clergy member of your faith, or call the hospital's Pastoral Care department for support and guidance
- Take pictures of the baby with each family member and with the family as a whole — you can never have too many pictures of your baby
  - \* If you did not bring a camera, we can provide one for you, or our staff can contact "Now I Lay Me Down to Sleep," a non-profit group that will send a professional photographer, free of charge, to take pictures of your baby

- Discuss funeral plans with your family and the grief counselor, nurse, or social worker - allow family and friends to help with calls and arrangements
- Do anything else that is important to your family
- Remember there is no time limit and no rush take your time

#### After the Hospital

- Some families will want to memorialize their baby there are no rules to this and no right or wrong way to memorialize your child
  - Plant a garden

  - \* Buy a special wind chime or figurine to place in your home or garden
  - Light a special candle on holidays
  - \* Take your hospital picture to a photographer to be touched up
  - ® Give a Christmas ornament to family and friends in honor of your baby
  - Make a donation to your favorite charity, or to the Forget Me Not Foundation, in memory of your baby
  - ® Provide literature or books for other bereaved parents in memory of your baby
  - \* Attend the annual Walk to Remember held in October



# Planning a Precious Goodbye

Planning burying or cremating your child is a very difficult and stressful experience. No parent ever imagines burying his or her baby. It goes against every law of nature and every family's plan.

Taking time to make the right decisions now will aid in the grieving process. Follow your heart and do the things that feel correct and you will be able to look back with few or no regrets.

If you are need of financial help, a funeral director should be able to direct you to the proper authorities in your county. Most funeral directors do not charge for their services. Usually, the only cost is for the burial.

#### **Making Decisions**

Don't let anyone rush you to have the service immediately, or even a few days after the loss. There is no time limit for when the service has to be performed unless there are cultural or religious traditions.

Even though this is a very stressful and painful time, try to make the most of your own decisions. If you let others make the plans, it becomes their service and their tribute.

#### **Choosing a Funeral Home**

Choose a funeral home with care. Finding a funeral home and funeral director who will provide you with choices, as well as support your wishes, is important. Feel free to ask any questions about services and costs before you select a funeral home.

The funeral home and your place of worship will give you ideas of what types of funeral or services are available.

Make the choice that seems right for you as parents.

# The fourney of Grief

This section has been written to help guide you through your grief journey. It certainly isn't all-inclusive, but hopefully, in reading this, you will identify with some of the experiences one might go through. You will come to believe that grief is a normal process with no timetable for healing. Grief is heartbased, not logic-based. Every person's grief is unique - no two people grieve alike, even if the loss is the same. Grief is as deep as your attachment to the baby. The journey of grief is difficult and life-altering.

#### **Common Myths of Grief**

- All bereaved parents grieve in the same way
  - \* Truth: Everyone grieves differently, in his or her own way, and in her or her own time
- lt takes two months to "get over" your grief
  - \* Truth: You never "get over" your grief you get through it
  - \* Truth: It takes different people different amounts of time
  - \* Truth: The most intense grief may last 18-24 months or longer
- Once grief is reconciled, it never comes back
  - \* Truth: Grief may return on holidays, birthdays, or on anniversary dates
- You and your family will eventually be the same as you were before your baby died
  - Truth:: You are never the same you can choose to grow from this experience rather than become bitter from your loss
- t is not appropriate to feel sorry for yourself
  - \* Truth: Prolonged self-pity is not healthy, but initially is a coping mechanism
- There is no reason to be angry over the loss of your baby
  - Truth: Anger is a very normal feeling following the loss of your baby feelings are neither right or wrong, they simply exist
- Children need to be protected from grief and death
  - Truth: Death is a sad, but normal part of all of our life experiences, and children should not be excluded
- 🗫 Once a baby has died, it is better not to focus on her or him, but put your baby in the past and go on into the future
  - \* Truth: This baby is a part of your book of life; talking about and remembering your baby is a way to heal
  - \* Truth: Embracing your pain is not easy, but will lead you to be reconciled with your loss

## Ten Ways to Find Hope & Heal Your Heart

- 1. Be open to the presence of your loss
- 2. Dispel the myths of grief
- 3. Embrace the uniqueness of your grief
- 4. Explore your feelings of loss
- 5. Recognize that your feelings are normal
- 6. Understand the needs of mourning
- 7. Nurture yourself
- 8. Reach out for help if you need it tell people what you need and want
- 9. Seek reconciliation, not resolution, for your loss
- 10. Appreciate your transformation

As a parent, you will never get over the loss of your baby, but you will learn to live without his or her physical presence and, eventually, integrate their loss into your life's experience. That you've been changed by your baby's death is undeniable. Your personal rules and ways of interacting with the world will be different now. The changes in you will be a lasting testament to your baby's existence.

What is important to know is that you can and will move through your grief. Knowing and understanding that grieving is a process can help diffuse feelings of powerlessness and provide some measure of consolation, hope, peace, and healing.







# Three Realities of Grief

#### 1. You will arieve:

Grief cannot be avoided. Grief is a mystery to be lived, not solved. Learning what the common experience on the grief journey are will help you get through it.

#### 2. You will have many different experiences:

There may be waves of disappointment, sadness, anger, despair, fear, guilt, and poor self-esteem. You have to learn to be patient with yourselves and others.

#### 3. You will need support:

Often it does not come from family and friends as expected. You may need a special person or group. You need a companion on your journey.

It is not uncommon to be afraid of the grieving process. It is scary. Some of the fears you may experience are loss of control, appearing weak to others, or tears that will never stop. You may feel that you will be unable to bear the loss and that, in time, the baby will be forgotten. These are normal fears that you will overcome.

The grieving process is often divided into four phases. These phases overlap and you may move backward and forward through them.

# Four Phases of Bereavement

#### 1. Shock and Numbness

- These characteristics are the most intense the first two weeks and then often reappear near the first anniversary dates
- The feelings can include:
  - \* Fear, panic, feeling out of control, powerlessness, restlessness, difficulty concentrating, inability to make decisions, loss of memory, confusion, outbursts of anger, hostility, denial
- Accept these feelings as normal this is your necessary introduction to grief

#### 2. Searching and Yearning

- These characteristics are the most intense from the 2nd week to the 4th month, at the first anniversary, and on special occasions
- These feelings force you to confront the fact that life will never be the same – you will have a new sense that life is unfair
- **c** Emotional symptoms can include:
  - Searching mentally for your baby
  - Searching for answers or the cause of the loss
  - Looking for someone to blame
  - Having bizarre thoughts and feelings
  - \* Heaving jealousy towards other parents
  - \* Feeling anger at God, doctors, your partner
  - Being preoccupied with details
  - Questioning "why?"
  - Dreaming about your baby
  - \* Obsession to become pregnant again
- Physical symptoms can include:

  - \* Having arms that ache to hold your child
  - ® Experiencing pains, loss of appetite, headaches, insomnia, and heart palpitations
- Feeling empty

### 3. Disorganization

- These feelings are the most dominant between the 5th and 9th month
- This will be a time of ups and downs you may feel that life will never be good again and that many ordinary things are difficult
- Relationships can be difficult at this time because grief tends to make each parent self-centered - at the time when parents need to support each other the most, they are the least able to do so
- Relationships with family and friends can be impacted because they do not understand the depth of the parent's loss
- A feeling of guilt will be overwhelming parents can feel responsible for the death of their child, as they will feel that they should have been able to protect them
  - \* Guilty feelings must be identified, clarified, and put to rest

- Anger is a very strong emotion that cannot be put to rest until it is discussed and expressed - denying deep feelings of anger can lead to resentment and bitterness
- During times when life feels like it will never be good again, a support group can help to work with you to understand and accept your grief
  - \* Antidepressants should generally be avoided unless you took them before the death of your baby
- Thoughts and behaviors during this phase can include:
  - Feeling empty, lifeless, or hopeless
  - & Loss of interest in activities you previously enjoyed
  - Neglect of personal appearance and daily tasks
  - Feeling trapped in your mourning
  - \* Excessive guilt, fear, and preoccupation with the loss
- Some physical symptoms can include:
  - \* Change in eating patterns, dry mouth, nervousness, listlessness, lack of energy, more frequent illness

#### 4. Reorganization and Reconciliation

- These characteristics are most dominant from the 18th to the 24th month
- Grief is something that happens to you without a choice, but recovery from grief involves a choice
- You can choose to become bitter or better
- Section Everyone is changed by personal crisis many come away with a new purpose and direction
- The exhaustion from grieving can be similar to a heavy physical workout, and can include the following symptoms:
  - Chest pains or shortness of breath
  - Dizziness
  - Dry mouth
  - Empty feeling in abdomen
  - Fatique or lack of energy
  - \* Feelings of having something stuck in your throat

  - Sleeping problems
  - & Loss of sexual desire, or having an overly active sexual desire
  - Weight gain or loss
  - Blurred vision
  - Uncontrollable sighing or sobbing
  - Weakness of the muscles
  - \* Gastrointestinal symptoms including constipation, diarrhea, or
- Any of these symptoms can be a normal part of your grief experience, but if the symptoms persist with no relief, make an appointment with your physician — remind him or her that you have just suffered a major loss.

# Your Body Ofter the Loss of Your Baby

Your mind will know that your baby has died, but your body will not. It will continue to function as though your child lived, and will prepare to help feed and nurture your baby. You will also have to go through the physical post-partum symptoms that come from child birth. At this time, it is common to feel betrayed by your own body, but you must remember to take care of yourself.

You will continue to bleed after giving birth, and that bleeding will continue for the next 4-6 weeks. Your uterus will be changing back to its size before the pregnancy, so cramps are common for the first 6-8 week as well. You should not do any heavy lifting or physical activities during the first few weeks after giving birth to avoid any complications, and for about a month if you had a cesarean birth. You should not have sexual intercourse or use douches or feminine products in your body for at least six weeks. Continue to check in with your doctor to ensure there are not any complications or infections following childbirth, just as you would normally.

Your breasts will start to lactate during this time. This is another reminder that you have lost a baby, but can also work to validate the fact that your baby is real. You can choose to pump for as long as you'd like. It is most important for you to feel comfortable. If you decide to stop pumping, manually release milk to relieve tension only when necessary. After a few days, your body will stop producing as much milk and the milk will be absorbed back into your body. If you would like to donate your breast milk to mothers who cannot lactate, there are several organizations that you can work with, and they are easy to find online or in your local area. Wearing a sports bra, along with using ice packs and breast pads, can help with any discomfort or pain that your breasts are feeling.

Give your body time to heal and take this time to forgive your body if you are feeling anger towards it. Marvel in its healing abilities and observe all the changes that it makes.

## **Emotional and Psychological Effects of Grief**

hen a baby dies, it is impossible to anticipate the full impact that loss will have on your life. Often, it leaves your life in compete upheaval. Emotions and feelings are helter-skelter. Tears are mixed with anger; sadness and loneliness seem overwhelming. Know that it is okay to cry. Know that it is okay to be angry. Feelings are neither right nor wrong; they simply are.

If you feel guilty about something you did, or something you did not do and think you should have done, now is the perfect time to sit down and write a letter to your baby or journal your feelings. If you are completely honest with yourself, you know that you would have done anything to have a healthy, living baby. Not expressing your emotions allows them to have control over you.

#### Some physical and emotional manifestations of grief can include:

- Denial
- Guilt 🕏
- Anger
- Resentment
- Bitterness
- Depression swings
- Time confusion
- Irritability
- Sense of failure
- Sadness
- Concentration on problems
- Failure to accept reality
- Preoccupation with the baby
- Fluctuation of moods
- Decreased self-esteem
- Dreams

#### Some ways to deal with your emotions include:

- Exercise this can offer a physical and mental release of tensions
- Cry tears of grief have toxins that your body needs to release
- Talk about your feelings joining a support group can help if you feel comfortable
- Write express your thoughts to yourself, your baby, your partner, your doctor, to your God; write to whoever you feel you need to write to. You may choose to destroy your writings or put them away in a special place
- Pray this will help you cope with the necessary pain and adjustments that follow your tragedy
- ✿ Meditate and relax this can offer you a brief respite from your emotions
- Drawing, singing, dancing, or any type of creative outlet
- ✿ Watch a funny movie this can offer a diversion from your grief; it is okay to laugh
- Be grateful and practice gratitude an attitude to gratitude can be difficult in the beginning, but will be an important aspect of your healing

You may or may not have some or all of these emotional feelings. As long as they come and go, this is a normal part of grief. It can be very difficult to realize that this is the price of love. Things will get better. Working through your grief by facing it head-on is difficult, but healing. There is a light at the end of the tunnel.



#### Social Effects of Grief

#### After the loss of a baby, you may find yourself in a different place socially, and might find yourself doing the following:

- Avoiding people, places, or things that remind you of your loss
- Feeling isolated from others
- Feeling left out of activities you did as a couple, with friends, or with family
- Feeling misunderstood by friends and family; no one ever talks about the baby
- Refusing to try new things like a support group
- Refusing to celebrate the holidays because of the anticipated pain of being reminded of the baby's absence
- Overworking or becoming a workaholic
- Becoming too busy as a way to avoid pain
- Not going to family gatherings
- Not wanting to be around friends or family with babies for a while
- Going away for the holidays
- A Not being able to go to a baby shower



You are no longer the same person or couple as you were before. The loss of a baby, with all of its lost hopes and dreams, changes you forever. That doesn't necessarily mean something bad; experiencing the mystery of grief and growing better or bitter is a choice only you can make. The more you open yourself to the pain, actualizing the meaning in your life, the sooner your real healing will occur. Love never dies.

There is no right or wrong way to do things. There will be people who think they know exactly how you should feel or act, and they will probably tell you their opinions. Many people mean well, but no one but you knows exactly how you feel and even that can change moment to moment. Most people mean well and feel they have to try to "fix" your pain. They probably feel helpless also. No one can ever know what your pain feels like. Tell people what you need and want.

#### Below are some suggestions to help you cope with criticism from yourself and others:

- 🗫 Realize that you may be oversensitive at times you may be reading into people's statements and actions or feelings that aren't there
- 🕸 Determine right and wrong for yourself and don't let others force it on you ; only you have the right to determine how you feel
- 🗫 You are the only one to assume responsibility for your health and happiness, and you don't need others to determine how you should do this

# **Spiritual Effects of Grief**

We are accustomed to think that if we just had enough faith, we would not have any doubts. Some soldiers are accustomed to thinking that if they had enough bravery, they would not have any fears in battle. Some grieving parents think that if they just had enough faith, they would not feel any sorrow. In contrast, faith as courage suggests that faith is trusting God in spite of one's doubts, that bravery is action in spite of one's fears, and that faith is hope in a new tomorrow in spite of one's present sorrow.

#### Some of the spiritual effects of grief could possibly be one or more of the following:

- Looking at and accepting our own mortality
- Finding meaning in God that we never had before
- Turning away from God
- Asking piercing questions, such as "Why would a loving God let this happen to us?"
- Staying angry with God
- Becoming more reflective on spiritual matters
- Finding comfort in prayer or spiritual readings
- Feeling abandoned or punished by God or our belief system
- rinding no comfort in prayer or our belief system
- Finding comfort in God or our belief system
- Examining our own lives and how we wish to spend the remainder of them

## How Will I Know I'm Feeling Better?

The answer to this question will vary for everyone. For most people, the process of grief recovery is a process of "one step forward, two steps back." It is not uncommon to have a good day or a happy moment, and then to have a few bad days.

Although it is so hard to imagine in the first few days, you will experience happiness - even joy - again. When this first starts to happen, parents sometimes report feeling guilty, or like they are leaving the baby behind. Gradually they are able to see that their baby will never be forgotten, and that feeling good is not disloyal.

One day, you may notice that you are interested in social interaction again. You may have made new friends, or you may want to reconnect with old friends. Your abilities to concentrate and to feel pleasure will start to return. You will discover that you will never be the same again. You may see qualities in yourself that you never saw before. You may feel more compassionate to others who are going through tough times and reach out to them, knowing they need someone's presence more than words. You may grow to feel your baby's presence within you.

A few more things you can do to help yourself include:

- Reach out to people who "get it" – spend time with friends and family who are able to tolerate your intense feelings in a loving, supportive way
- r If you are having difficulty sleeping or eating for more than a few weeks, it is important to contact your physician
- Listen to your inner needs and make some changes in your life
- Recognize that grief is carried with you throughout your life, but it is your choice how it is carried - you can carry your grief as a victim, or as a courageous warrior
- Try a support group as a place to give and to receive

















# 

As a couple, you may sometimes notice that your baby's death affects your relationship - sometimes for better, sometimes for worse. You may alternate between intimacy and isolation. You will discover that you may not grieve and react in the same manner and at the same time. This may be the first tragedy you've faced together, and you may discover new ways of being there for each other. Sometimes the stress of grieving can make you so needy individually that it can be difficult to support each other. Often you will grieve very differently from each other, making it difficult for you to empathize or accept each other's feelings or what may seem like lack of feelings.

Distinct styles of grieving can be attributed to normal variations in personality, family backgrounds, philosophy, coping styles, and, for women, hormonal changes. Mothers and fathers also grieve differently because they usually feel different levels of bonding to the baby. There is no right or wrong here. Give yourself permission to have your own feelings. You are each entitled to your own feelings.

Take responsibility for your actions. They rise out of your perceptions and your body. No one can "make" you feel a certain way. Instead of blaming your partner for making you so angry, crazy, fearful, or sad, accept these feelings as your own. Instead of seeing yourself as a victim, accept responsibility for these emotions and feelings. In doing so, you will also claim the power to face and deal with them. If you can understand where these emotions come from, you may feel less threatened by them.

It is important to avoid judging your partner. By simply accepting their feelings, you are acknowledging that he or she is entitled to his or her feelings, just as you are entitled to yours. You may not share your partner's feelings; you may not always understand them. You may even feel angry or disappointed at your partner's reactions. By accepting each other's silences and tears without judging or placing blame, you encourage non-threatening communication. You also provide the kind of support and understanding necessary to promote healing and to enhance your relationship.

Change will occur in both partners as the result of your baby's death. Many changes that occur can give rise to conflict. Some conflicts that might arrive include:

- Searching for and adopting new philosophies, perspective, goals, desires, and assumptions about your life, its meaning, and direction
- Questioning your religious beliefs and faith
- Having a new awareness of your needs and emotions
- Wanting to become more assertive and expressive
- Dealing with a resurgence of grief from past losses
- Having different intimacy needs
- Experiencing different desires for another baby
- Having disagreements about handling your other children's feelings and behaviors
- Disagreeing about how much information you share with other people, such as information about difficult decisions, experiences, feelings, and other personal
- Experiencing the end of the honeymoon period that existed around the time of death
- Accepting the differing ways you both adapt to change
- Have different levels of tolerance for conflicts or distance

Acknowledging these changes and conflicts can help you weather them. It may also help you and your partner to openly discuss these matters. Listening without trying to "fix" the other is key. Write a letter to your partner describing your feelings can be very healing. Grieving is a process that takes time. The key ingredients to help your relationship survive and grow, despite this tragedy, are caring about each other, sharing thoughts and feelings, accepting your differences, and reassuring your partner that you are committed to the relationship.

## Fathers Grieve, Too

Most of the time, dads are neglected grievers. While we know a lot about the grieving process, people still aren't sure how to respond to a man's feelings. It is safer to ask how the mother is doing than to ask how you feel. Among other things, you may feel:

· Hurt Angry Angry Empty Depressed Sad 🕏 Guilty Lonely Afraid Helpless Out of control Hopeless Like a failure Confused Frustrated Disappointed

These are all normal emotions. This can be one of the toughest times of your life, and it's important to take care of yourself. You may find that you are taking care of everyone else, making all the arrangements, and doing all of the work. After the funeral or memorial service, people are likely to expect you to act as if nothing happened. Grief, with its many ups and downs, lasts far longer than society in general recognizes.

You may be afraid of the mother's emotions and try to "fix" them. She may vacillate between appreciating this and resenting it. As you begin to get back to your normal activities, you may find your feelings popping up when you least expect them. You may feel like you are going through the motions of living. You may feel distant from people, and you may find yourself unusually angry.

#### **Anger**

Men and women grieve differently. Women have more permission to cry and talk. Men have more permission to be angry. It is okay to be angry when your child dies. It is unfair, unjust, and an angry situation. The biggest problem with anger is where to direct it. Many times, the anger is directed towards your family. You may want to recognize how you're sharing your anger. Talking to another dad whose baby has died, or visiting your pastor, nurse, social worker, counselor, or just a friend who can see things more clearly, can be helpful.

#### **Talking**

One of the things that can help is talking about your child. You have strong, cherished memories. Whether the memories are of the pregnancy and your plans for the baby, or the actual experience of the death, talking may lighten your pain, clear your anger, and affirm your feelings.

#### Your Relationship

A lot of people think a child's death makes a couple closer. Sometimes it does, but often parents are so wiped out with their own grief that they can't lean on each other. Each person's grief is so individual. It is vital not to have unrealistic expectations from each other. You and your partner will experience grief and cope with it differently.

After years of hearing "big boys don't cry," we've finally learned that real men do. Crying is an acceptable and healthy expression of grief and releases built up tension for mothers, fathers, brothers, and sisters. Cry freely as you feel the need.

While it is important that fathers have the opportunity to grieve the loss of your baby, there can be behaviors that can cause lasting changes on your marriage or partnership. Some signs of deeper troubles can include an increase in drinking, an increased interest in work and time spent at work, increased time spent away from the home with friends and family, extramarital affairs, or a sense of resentment towards your wife. At times it can seem like the mother gets the majority of the attention and sympathy, but that is not a reason for resentment. Ask for help when you need it and talk to friends and family when you can. If you do not feel like that is helping, talking to a therapist or counselor can be the right choice. Men and fathers can be vulnerable also, and you should not forget that during this emotional time.



# Intimacy and Sex Ofter the Loss of Your Baby

As a couple, you must recognize that grief probably will have an impact on your sexual relationship for a while, and that this may be totally unrelated to your feelings of love for one another. For some couples, sex provides the intimacy and reassurance they need from each other. However, when they feel depressed or angry, or when communication breaks down, sex may be the last thing they desire. For many parents, the link between sex and conception is painfully obvious. For others, the associate between sex and affection makes them feel hurt by their partner's lack of desire. Mothers must also cope with natural postpartum physical and emotional changes that can make them less responsive.

Sexuality and physical closeness are biological needs that seek balance. As with grief, sexuality after a loss is unique to each person. By coming together sexually after the loss of a baby, a couple may be able to briefly put aside their grieving and feel close to each other, connecting themselves to the flow of life again. It is not uncommon for couples to need tenderness and nurturing more than intercourse initially. Further, some women or men may have an aversion to sex at first because they feel their present agony had its beginning there. Fear of a new pregnancy and, by extension, the possibility of the pain doesn't have to be faced. Guilty feelings may interfere with enjoying one another.

Depression is part of the grief experience. Depression can temporarily cut off feelings of sexual desire, which is completely normal in both men and women. It is important to talk openly with your partner about your feelings and anxieties so that your reactions won't be misinterpreted. Negotiating your sexual relationship requires more nurturing, sharing, acceptance, and reassurance. Be sensitive to both of your emotional needs during this stressful time. By talking, listening, and hold each other, you can maintain feelings of intimacy and affection without the pressures of intercourse. With patience, mutual tolerance, and understanding, the problems will resolve themselves as healing progresses. Getting away to be alone together may help. If problems persist far into the second year of grieving, seek professional help.

Grief will change each of you individually, as well as your marriage and family as a whole. It is not something that needs to be feared, but rather an opportunity to grow.

#### **Questions to Reflect on Yourself:**

- What are my needs regarding closeness, sensuality, and sexuality What would be good for me?
- What is it I don't want at this time?
- Do I allow myself sexual feelings, or do I think that would not be okay for me at this time?
- Am I afraid of sex because theoretically it could lead to a new pregnancy and another loss?
- Can I talk openly with my partner about my feelings and needs, and also about what may not be possible right now?
- f we haven't been sleeping together, how does that affect me? What can I do to prevent too much tension from building in me?
- f our relationship is troubled right now, with whom can I talk about it?
- Are our difficulties serious enough to warrant professional help?

As a couple, you may want to write down answers individually to these and other questions and come together to share your thoughts and feelings. It is an excellent way to communicate and come to some understanding.

#### **Suggestions for Couples**

- Let your relationship be your number one priority
- Be patient with yourself and your partner
- Try to accept that your partner isn't at the same place in their grieving process as you are
- Strive for openness, honesty, and kindness in your communication
- Allow your own feelings: communicate what goes on inside of you and give your partner the chance to express his or her pain
- Give one another room to grow in the relationship
- Work at increasing your affection, caring, and respect for each other
- Discover ways to nurture and express these feelings
- chance one another's healing through physical closeness and touch
- Encourage one another to enjoy life and each other
- Laugh together, cry together, and discover things to do together that bring you joy
- Find support from sources other than your partner
- Nurture the thought together that, as precious as your baby is to you, there is still so much worth living for

## Pregnancy After Loss

t is important not to rush getting pregnant immediately after losing a baby. It might feel like there is a void in your family that needs to be filled, but this should not be filled by a new baby. Every family is different when it comes to grief and the time it takes to be ready to have another baby. There is no time frame or time limit that needs to be adhered to when considering trying to have another baby, but be sure to consult with your doctor to ensure that your body is ready to carry another child. The conversations with your partner are the most important, and make sure that you are both honestly on the same page about having another child.

Once you become pregnant with a new baby, you will feel many different emotions. You will likely feel afraid that this baby will also die. You might feel guilt towards your lost baby, as if this new pregnancy will replace your baby. You will be excited to welcome a new family member into your life, but you might feel anxious that your body or anxiety will negatively impact this new baby. Make sure you are talking about your feelings with your partner, along with a counselor or doctor. You are not in this new pregnancy alone, and should not have to feel isolated in your feelings.

Finding or choosing a doctor for this pregnancy can be a challenge. Some families feel familiar and comfortable with the doctor and team that were with them for their last pregnancy. They don't look forward to retelling the story of their loss, and this team has experienced it and knows their history. However, going back to the same place that the loss occurred can also be troubling and can increase anxiety. Talk with your family about this decision, and make the choice that feels the best for you and your future baby.

When your new baby is here, do not be afraid to celebrate. Loving this baby does not mean you loved the baby you lost any less, and celebrating this life is not forgetting the other. As your child grows. you can decide to share the story with them of the baby that came before them, and the journey that you went on with their sibling. Being overly-protective of this baby is very common, but should not stop you from living your life and enjoying this time as a parent.

# Helpful Information

# Sharing with Family, Friends, and Employers



# Children Who Have Lost a Sibling

uring this time of loss, you may be tempted to try to shield your other children from completely understanding the loss that your family has just had. This may seem like a mercy at the time, but your entire family has suffered a loss and should be able to grieve together. It might not make sense to share all of the information with your children depending on their age, but there are some suggestions for how to discuss this death with your other children so that they can also grieve for their sibling.

Explaining death to a child can seem like a dauting task; they will likely already know that something is wrong as they will have observed their parents mourning. It is important not to over-explain death to your children. The main thing that they need to understand is that death is final; their baby brother or sister will not be coming back, but they will still have the ability to talk about their sibling and remember them. Make sure they understand that they can ask you questions, and that they should not be afraid to bring up the baby. They need to talk about the loss so that they can understand it and understand their emotions about this experience. Give them a safe place to express their grief, just as you want a safe space to express yours.

Depending on the age of your children, the conversation about this death will be different. Younger children do not understand death as a concept, and this may be their first experience with a loss. They might be afraid that whatever happened to the baby will happen to them, and it might make them scared for you as parents as well. They might experience nightmares or trouble sleeping, as they are afraid they will not wake up. Reassure them that they are safe, and that you are safe as well. Make sure they understand that they did not do anything to cause this loss, and that they are safe, healthy, and loved.

Older children will understand better what happened, but they will still have questions and fears. The older the child is, the better prepared they will be to understand what has happened, but that does not mean that they will know how to respond or to grieve. Talk about their sibling with them and answer any questions that they have as honestly as you can. Take this time with your children to celebrate and remember the life of their sibling, and work to incorporate memories of their sibling into aspects of your life. Your children might feel jealous of their lost sibling even in death, so they might ask for more of your attention. If they are acting out or are behaving to try to get your attention, make sure you keep any rules or guidelines that existed before the loss in place. It will not help them in the long run if you are overly lenient at this time. Try not to change too much of their normal routine, as they will need that stability now more than ever.

## **Grandparents and their Grief**

arents of children that are lost are not the only ones affected. Grandparents have some of the same experiences as the parents during the time that a mother is pregnant and can be just as devastated by a loss. Grandparents can have the same dreams for the unborn child and can plan their future lives just as parents do. When a baby dies, grandparents can sometimes blame themselves, trying to pin the reason for death on some genetic disease that they carried or not helping the parents enough during the pregnancy. Also, you will have to see your child hurting and not be able to fix it. Just like with parents, grandparents must understand that it is not their fault and placing blame will not help with the grieving process.

There are some things that grandparents do, however, that will not be helpful to your children during the grieving process. Try not to place blame on the parents, suggesting that if they had done something differently during their pregnancy that the baby would not have died. Also, give the parents their space and time to plan their baby's funeral or memorial on their own, unless they specifically ask for your help. They need this time to mourn, and if they are not involved in this planning it can cause regret later. Lastly, be open to your children whenever they need to talk or open up. They might distance themselves from everyone for a while; do not take this personally. When they do come to you, listen to them, offer a shoulder to cry on, and offer hope for the future.

#### SAMPLE LETTER TO SEND TO FRIENDS AND FAMILY

# My dear friend, family member, employer, and/or coworkers:

I have experienced a loss that is devastating to me. It will take time, perhaps years, for me to work through the grief I am experiencing because of this loss.

I may cry more than usual sometimes. My tears are not a sign of weakness or a lack of hope or faith. They are symbols of the death of my loss and the sign that I am recovering. I may become angry when there seems to be no reason. My emotions are all heightened by the stress of the grief. Please be forgiving if I seem upset at times.

I need your understanding and your presence more than anything else. If you do not know what to say, just touch my hand or give me a hug to let me know that you care. Please do not wait for me to call you. I am often too tired to even think of reaching out for the help and support that I need.

Do not let me withdraw from you. I need you more than ever right now. Instead, keep me in your thoughts each day. A card, a note, or a phone call to let me know that you are thinking of me may provide strength on a bad day. I may not always call you back. I will not always be up for talking, but I appreciate your support.

If you, by chance, have had an experience of loss that is anything like mine, please share it with me. It will not make me feel worse; sharing with others can often reduce the burden of individual pain.

This loss if very painful for me. Where there is love there is pain. But I will get through it and I will live again. I will not always feel as I do now. I will laugh again.

Thank you for caring about me. Your concern is a gift I will always treasure.

Sincerely,

# Thoughtful Ways of Supporting the Family

When a baby dies, no matter the gestational age, parents need to talk about their baby because it reaffirms the baby's existence. While it is very difficult to find the words that might help the grieving family, it is comforting to tell them, "I am sorry for your loss," or admit, "I don't know what to say." Letting a family know that you are there for them or that you are praying for them is also helpful. Even your tears are comforting.

Please do not make comments like "You'll get over it in time" or "You can always have another baby." It doesn't matter that there may be other children or that they can try again. The parents need to grieve for this loss. Try to be sensitive to this loss and the fact that, while time may ease their pain, they will never "get over it." Parents do not want their pain of grief and mourning to be "fixed." It honors the love and hopes that they had for this child. There is no replacement.

#### You can support the family if you:

- Stay available and listen. Listen to their story over and over again.
- understand that grief is not an easy upward climb. It is one step forward, three back, two steps forward, four steps back. There are continuous backslides that may frighten the griever, catch the griever off guard, and sometimes make him or her feel crazy. This is normal.
- Always respond in a non-judgmental way.
- Send "Thinking of You" cards.
- Visit or call the family often.
- Tell the family you would like to help with any task they might need of you.
- Recognize that, although it is wonderful that your children are alive and well, bereaved parents may be sensitive to other parents talking excessively about their children's achievements and good fortune. Their deceased baby will miss so many opportunities for birthday parties and all that goes with childhood.
- Acknowledge that the baby existed and accept and share the parent's grief. The parents may want to share their pictures with you.
- Be sensitive to the family's mixed feelings about your own or a friend's pregnancy. It may be very difficult for the grieving parents to see a friend or relative who is pregnant or whose baby may be due at the same time as their baby. Baby showers and family gatherings can be very painful to the parents.

- Remember especially difficult times, such as the anniversary of the baby's due date, birth date, or death date. Remember the baby on the holidays.
- Remain patient. People grieve differently and for different lengths of time. Fathers are usually asked how their wife is doing. Ask the father how he is doing. Often men grieve in more solitary ways. Women may be more outward in their mourning and be quicker to reach out for help, or to go to a support group. Parents never "get over" the loss. They learn, in time, to be reconciled with the death and will learn to incorporate the baby into their book of life.
- Offer to look at the memorabilia from the hospital.
- Encourage the bereaved family to attend a perinatal bereavement support group. Ask about the groups we offer, and local groups for grandparents and family members.
- A Never dismantle the nursery or put away baby clothes, unless the parents specifically ask you to. That is part of their grieving process.
- Avoid giving advice, medical or otherwise, and avoid blaming people, situations, and so forth.
- Don't be afraid of making the parents cry if you bring up the baby's name. It will be a good cry.
- Your love, caring, patience, listening, and most importantly your continued support, will be the best medicine for healing.

# **Organizations and Websites**

#### **Bereaved Parents USA**

www.bereavedparentsusa.org

The national organization educates and nurtures families who have lost a child at any age from any cause.

#### **The Compassionate Friends**

www.compassionatefriends.org

A national, non-profit self-help organization, The Compassionate Friends offers companionship, understanding, and hope to families who endure death of a child at any age.

#### First Candle

www.firstcandle.org

When the National Sudden Infant Death Syndrome Alliance grew to include stillbirth in its advocacy and support efforts, it changed its name to First Candle. The organization provides information for parents, caregivers, and health professionals and supports families after the death of their baby. It serves as an intermediary among government, healthcare professionals, community-based groups, businesses, researchers, and scientists, as well as parents and caregivers.

#### The Forget Me Not Foundation

www.fmnfoundation.org

This non-profit was established by bereaved parents and supports families suffering from pregnancy or newborn loss. FMN provided this pamphlet and other bereavement materials and education to Hackensack University Medical Center.

#### International Stillbirth Alliance

www.stillbirthalliance.org

Centralization is the key theme of the Alliance, which is a nonprofit coalition of organizations devoted to understanding the causes of stillbirth. Its mission is threefold – to raise awareness, educate on precautionary practices, and facilitate research on the prevention of stillbirth.

#### Remembering Our Babies

www.october15th.com

This group's goal is to help others relate to parents who have lost babies and to help them know what to say and do. It offers ideas on how to specially honor the passing of a baby, both at the time of death and as the years go by.

#### **SHARE Pregnancy and Infant Loss Support**

www.nationalshareoffice.com

Nondenominational and international, SHARE supports people whose lives have been touched by death of a baby. Its information packets are free to bereaved parents. SHARE also sponsors gatherings for healthcare professionals



## Baby Product Mail: How to STOP Mailings

New parents frequently receive mail from companies promoting baby products, photography services, and other baby related items. If you would like to stop these mailings to your address, you can contact the Direct Marketing Association. Many of the catalogue companies, retailers, and service organizations that mail advertisements to your home belong to this trade organization. By contacting the address below, you can remove your baby's name from the mailing lists used by these companies.

When you register, the person's name, address, and phone number is placed on a special Do Not Contact list. The companies participating in this program are required to eliminate these names from their commercial marketing lists. The number of commercial contacts should begin to decrease within three months.

- complete this form and send it to: Direct Marketing Association, Mail Preference Service, PO Box 643, Carmel, NY 10512.
- Or, you may complete the form online at www.dmachoice.org. Follow the line to Consumer Assistance. A verification fee of \$1 will be charged to your credit card.

#### Please register my name with the Mail Preference Services

Name (Baby's name and/or Parent's Name):				
Street:				
City:	State:	Zip Code:		
Signature:				

# Resources

# **Perinatal Loss: Suggested Books**

Arnold, Joan Hagan & Gemma, Penelope Bushman. A Child Dies - A Portrait of Family Grief. Philadelphia, PA: The Charles Press, 1994.

Ash, Lorraine. Life Touches Life: A Mother's Story of Stillbirth and Healing. Troutsdale, Oregon: NewSage Press, 2004.

Bereavement Services. A Father's Grief. Gunderson Health System, 1984-2012, bereavementservices.org.

Bereavement Services. Grief of **Grandparents.** Gunderson Health System, 1984-2008, bereavementservices.org.

Bereavement Services. Talking With **Children About Perinatal Loss.** Gunderson Health System, 1984-2010, bereavementservices.org.

Bredwell, Debra, The Ache For A Child. Wheaton, IL: Victor Books, 1994.

Davidson, Glen, Ph.D. Understanding Mourning. Minneapolis, MN: Augsburg Publishing House, 1984.

Davis, Deborah L., Ph.D. Empty Candle, Broken Heart – Surviving the Death of Your Baby. Golden, CO: Fulcum Publishing, 2000.

Davis, Deborah L., Ph.D. Loving and Letting Go - For Parents Who Decided to Turn Away from Aggressive Medical Intervention for Their Critically III Newborn. Omaha, NE: Centering Corporation, 2000.

Diamond. Kathleen Fair. Motherhood after Miscarriage. Hollybrook, MA: Bob Adams, Inc., 1991.

\*Dodge, Nancy C. Thumpy's Story - A Story of Love and Grief Shared. St. Charles, MO: National SHARE Office, 1986.

Dominica, Sister Frances. Just My Reflection - Helping Parents To Do Things Their Way When Their Child Dies. London: Darton, Longman, and Todd, LTD: 1997.

Douglas, Ann & Sussman, John, M.D. Trying Again. Blue Ridge Summit, PA: National Book Company, 2000.

Faldet, Rachel & Fritton, Karen. Our Stories of Miscarriage - Healing with Words. Minneapolis, MN: Fairview Press, 1997.

Klein, Annette, R.N., Limbo, Rana, Ph.D., R.N., PMHCNS-BC, F.A.A.N., & Richardson, Kathleen, B.S.N., R.N., Bereavement Services. Caring For Yourself After a Loss. Gunderson Health System, 2010-2013, bereavementservices.org.

Kohn, Ingrid, M.S.W., Moffit, Perry-Lynn, & Wilkins, Isabelle A. A Silent Sorrow -Pregnancy Loss: Guidance and Support for You and Your Family. New York, NY: Routledge, 2000.

Lafser, Christine O'Keefe. An Empty Cradle, a Full Heart. Chicago, IL: Loyola Press, 1998.

\*Lanham, Carol Cirulli. **Pregnancy After Loss** - A Guide to Pregnancy After a Miscarriage, Stillbirth, or Infant Death. New York, NY: The Berkley Publishing Group, a division of Penguin Putnam, Inc., 1999.

Levang, Elizabeth & Ilse, Sherokee. Remembering with Love: Messages for the First Year of Grieving and Beyond. Minneapolis, MN: Deaconess Press, 1992.

Limbo, Rana & Wheeler, Sara. When a Baby Dies: A Handbook for Healing and Helping. Lacrosse, WI: Bereavement Services/RTS, Gunderson Lutheran, 1998.

Lipson, Juliene G., Dibble, Suzanne L., and Minarik, Pamela A. Culture and Nursing Care: A Pocket Guide. San Francisco, CA: UCSF Nursing Press, 2000.

Lothrop, Hannah. Help, Comfort, and Hope after Losing Your Baby in Pregnancy or the First Year. Tucson. AZ: Fisher Books. 1997.

Martin, Joel & Romanowski, Patricia. Our Children Forever. New York, NY: Berkley Books, 1994.

McCracken, Elizabeth. An Exact Replica of a Figment of My Imagination: A Memoir. New York, NY: Little, Brown, and Company, 2008.

McDonnell, Zchantell. The Night I Held an Angel. Bloomington, IN: Author House, 2004.

Miller, James E. How Will I Get Through the Holidays? 12 Ideas for Those Whose Loved One Has Died. Fort Wayne, IN: Willowgreen Publishing, 1992.

Moe, Thomas Rev., Dr. Pastoral Care in Pregnancy Loss: A Ministry Long Needed. Binghamton, NY: Binghamton Press, 1997.

Morrow, Judy Gordon & DeHamer, Nancy Gordon. Silent Cradle - Help and Understanding in Time of Pregnancy Loss. Indianapolis, IN: Light and Life Communications, 1998.

Nelson, James. The Rocking Horse is Lonely. Minneapolis, MN: Fairview Press, 1998.

Nelson, Timothy. A Father's Story. St. Paul, MN: deRuyter-Nelson Publications, A Place to Remember, 1994.

\*Nykiel, Connie. After the Loss of Your Baby - For Teen Mothers. Omaha, NE: Centering Corporation, 2002.

O'Connor, Joey. Heaven's Not a Crying Place: Teaching Your Child About Funerals, Death, and Life Beyond. Grand Rapids, MI: Baker Book House, 1997.

Reid, Joanie. Lifeline, a Journal for Parents Grieving a Miscarriage, Stillbirth, or Early Infant Death. Mullett Lake, MI: Pineapple Press, 1994.

Rosales, Jan Wolfe. Given in Love But Not Mine to Keep. Baltimore, MD: Erica House, 1999.



Notes: \*Schweibert, Pat, R.N. & Kirk, Paul, M.D. When Hello Means Goodbye. Portland, OR: Perinatal Loss, 2001. \*Schweibert, Pat, R.N. Strong and Tender - A Guide for the Father Whose Baby Has Died. Portland, OR: Perinatal Loss, 2000. Schweibert, Pat, R.N. A Grandparent's Sorrow. Portland, OR: Perinatal Loss, 1996. \*Schweibert, Pat, R.N. Too Soon a Memory: A Guide For Parents Suffering Miscarriage. Portland, OR: Perinatal Loss, 2000. \*Schweibert, Pat, R.N. Still to be Born. Portland, OR: Perinatal Loss, 2000. Tapp, Kathy Kennedy. No Smile Cookies Today. Wayzata, MN: Pregnancy and Infant Loss Center, 1998. (for children) Van Praaq, Judith. Creative Acts of Healing After a Baby Dies. Seattle, WA: Paseo Press, 1999. Vogel, Gary E., M.A., N.C.C. A Caregiver's Handbook to Perinatal Loss. St. Paul, MN: deRuyter-Nelson Publications, Inc., 1996. Wegner, Martha Hay. Embracing Laura: The Grief and Healing Following the Death of an Infant Twin. Omaha, NE: Centering Corporation, 1998. \*Wheat, Rick. Miscarriage - A Man's Book. Omaha, NE: Centering Corporation, 1995. Wolfert, Alan D., Ph.D. Understanding Grief: Helping Yourself Heal. Muncie, IN: Accelerated Development Inc. Publishers, 1992. Woods, James R. Jr., M.D., & Woods, Jennifer Esposito. Loss During Pregnancy or in the Newborn Period - Principles of Care with Clinical Cases and Analyses. Putnam, NH: Pittman-Janneti Publications. 1997. \*Titles with an asterisks (\*) next to them are available in Spanish. Most of these titles are available from the National SHARE Office or on Amazon.com.

