

GOODBYE BEFORE HELLO

Understanding Perinatal Loss



A RESOURCE FOR GRIEVING
PARENTS

PROJECT POPPYSEED

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INTRODUCTION

We offer our deepest empathy to those reading this booklet. The loss of a pregnancy or baby is one of the most difficult things a parent can experience.



ABOUT THIS BOOKLET

In this booklet, the term 'perinatal loss' is used to describe the loss of a pregnancy or baby from miscarriage, stillbirth, a life-limiting fetal diagnosis, or neonatal death. The booklet is intended as a resource for parents after they have experienced perinatal loss. How parents use the material is up to them. They may read it cover to cover the second they get home, they may put it away for a while, or they may return to different sections as needed.

Various topics are discussed throughout the booklet, including what to expect after returning home, when to contact your doctor, and how to understand the emotions you may be feeling.

Scan the QR code to
learn more about
Project Poppyseed



CONTENT OVERVIEW

This booklet is not comprehensive. You may have more questions than its content can answer. If you find yourself wanting more information, please do not hesitate to reach out to your care team.

Perinatal loss is more than a physical experience. In fact, most parents' concerns are emotional, existential, or spiritual. Examples of what is discussed throughout this booklet are listed in the box to the right.

HOPE AFTER LOSS

It may not feel like it, but it is possible to heal after perinatal loss. It will take time. Your grief will never go away, but you can learn how to live with your grief.

HOW TO USE THIS BOOKLET

This booklet addresses some of the physical, emotional, social, and spiritual questions, struggles, and concerns parents have experienced after perinatal loss. More information can be accessed using the QR codes on each page.

TOPICS

Physical Concerns

- Bleeding
- Lactation
- Hormonal changes

Emotional Concerns

- Grief
- Coping
- Healing

Social Concerns

- Partner relationship
- Talking with children
- Interacting with your social circle

Spiritual

- Anger
- Jealousy
- Hope



UNDERSTANDING GRIEF

Grief is work. There's no way around it. Living with grief after perinatal loss may seem overwhelming and impossible. You are not alone. The good news is that what you're feeling is normal, and that with time, you will learn how to walk beside your grief rather than be crushed by it.

Grief is not a linear process. There's no formula to make you "better" after experiencing perinatal loss. While each parent walks their own unique path, each path can lead to healing.

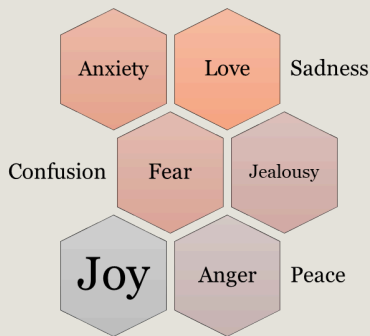
SOCIAL EXPECTATIONS

Unfortunately, society holds very specific expectations of how a parent should grieve after perinatal loss. This is because society in general does not understand perinatal loss. Social expectations of grief often cause parents more pain in their grief, leaving them feeling isolated and alone.

TASKS OF GRIEF

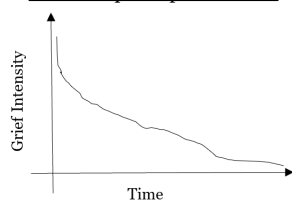
Dr. Worden, an expert on grief, explains the process of healing from grief as 'work.' As a person works through their grief, there are specific 'tasks' to focus on. There's no specific order to working through the tasks of grieving, but it is necessary to work on each task in order to heal.

EMOTIONS & GRIEF

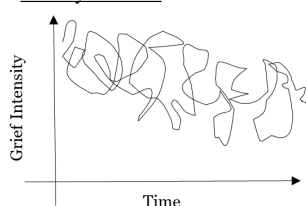


Grief is a unique experience, feeling these emotions does not mean there's something wrong with you.

What People Expect of Grief



Reality of Grief



Learn more about how to work through each task of grief.



PERINATAL GRIEF

“My grief will never go away, but each day I learn a little more about how to live with my grief. Each day my grief is a little bit lighter to carry.” (Amy)

WHAT IS PERINATAL GRIEF?

Perinatal grief is the universal, human response to the loss of a pregnancy or baby. Perinatal loss is a deeply personal experience and is one of the most misunderstood emotions in the human experience. Without personal experience, there's no way to relate to the emotions a parent feels.

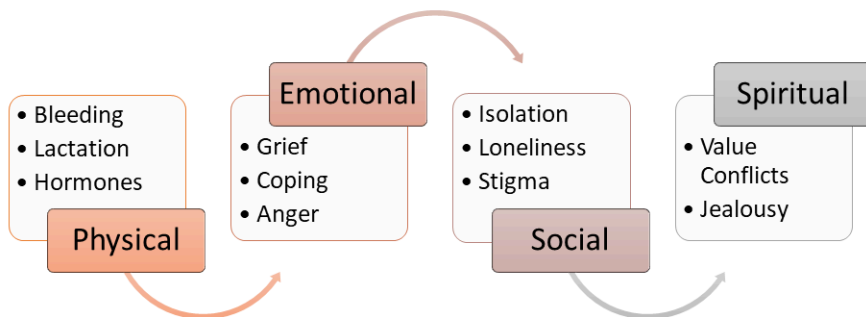
A UNIQUE LOSS

Perinatal loss, whether from miscarriage, stillbirth, or neonatal death, is not fair. It doesn't make sense. It goes against everything we expect in our world. Unfortunately, 25% of pregnancies end in loss.

Perinatal loss is different than any other type of loss. It's often a silent loss, one which the world would rather hide or pretend never happened. As a result, parents often feel alone and isolated. Parents may also feel many confusing emotions, such as anger, love, grief, joy, jealousy, the list goes on. There is no right or wrong way to feel after perinatal loss.

WHAT DO OTHER PARENTS EXPERIENCE?

Below are some of the things other parents who have experienced perinatal loss go through. The list provided is not comprehensive, and each parent's journey is unique.



PAIN & BLEEDING



RECOVERING FROM BIRTH

While your grief may be overwhelming, your body is also recovering after perinatal loss.

Depending on how far along you were when you lost your baby, your body will be experiencing different things.

EARLY PREGNANCY LOSS

Here are some things your body may experience after early pregnancy loss:

- Bleeding
- Vaginal Discharge
- Cramping

LATE PREGNANCY LOSS

Here are some of the things your body may experience after late pregnancy loss:

- Vaginal Soreness
- Vaginal Discharge
- Cramping
- Incontinence
- Hemorrhoids
- Hair Loss
- Skin Changes
- Tender Breasts
- Weight Changes
- Mood Changes

WHEN TO CONTACT YOUR DOCTOR

If you experience any of the following, you may be experiencing serious health complications and should contact your doctor:

- Heavy bleeding (saturate a pad in less than one hour)
- Passing clots larger than a golf ball
- Foul smelling vaginal discharge
- Fever and chills

Learn more about early pregnancy loss:



Learn more about late pregnancy loss:



HORMONAL CHANGES

One thing birthing persons rarely expect following perinatal loss is the natural changes in pregnancy hormones. There are four major hormones involved with pregnancy: estrogen, progesterone, oxytocin, and prolactin.

Postpartum depression, caused by hormonal changes following birth, is a common condition that may impact as many as 25% of individuals for up to one year following birth. For parents who are experiencing perinatal loss, hormonal changes causing postpartum depression can make processing grief even more difficult. Here are a few warning signs that are common with postpartum depression:

Emotional

Feeling Overwhelmed
Difficulty Concentrating
Feeling Dispair

Physical

Muscle Aches
Appetite Changes
Sleep Changes

Behavioral

Unable to find Joy
Avoiding Responsibilities
Withdrawing from Others

Grief

Debilitating Sadness
Overwhelming Anger
Emptiness

Estrogen

Helps the body begin the process of birth.

Progesterone

Prevents uterine contractions and lactation during pregnancy.

Oxytocin

Makes the uterus contract during birth.

Prolactin

Make breastmilk.

"Your hormones crash, or you have the Baby Blues, but you're also grieving. It's hard to understand what's going on and how to heal."
(Maya)



Learn about postpartum depression

If you notice two or more of these signs, you may want to talk to your doctor about postpartum depression

BREAST MILK PRODUCTION AFTER LOSS

BREAST MILK PRODUCTION CAN BE EMOTIONALLY AND PHYSICALLY PAINFUL

THE BODY DOESN'T KNOW

It's not fair that the body produces breast milk after perinatal loss. Many women are not prepared for their milk to come in. It can be emotionally as well as physically painful.

There are several options if and when your milk comes in. Some families wish to donate breast milk as a way to honor their baby. Others find donating breast milk too painful and wish to make it stop.

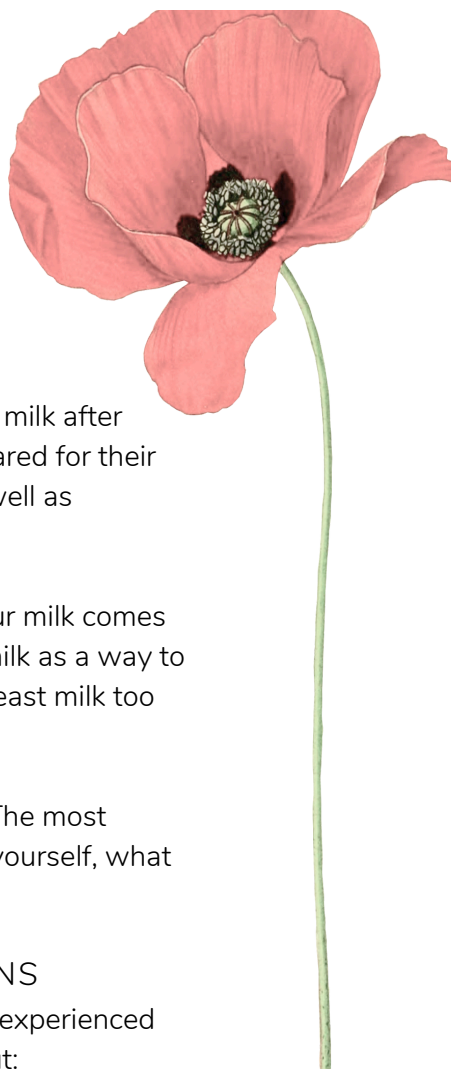
There's not a right or wrong thing to do. The most important thing is to make a decision for yourself, what is it that you need?

THE MOST COMMON QUESTIONS

Here are a few things women who have experienced perinatal loss wished to know more about:

- Milk suppression
- Pain management
- Breast milk donation

To learn more about breast milk suppression, donation, or pain management, scan the QR code.



SUPPRESSING BREAST MILK PRODUCTION

The body creates mature breast milk a few days after birth. When the milk remains in the breast, the breasts can become swollen and painful.

Hand expressing small amounts of breast milk can signal the body that it's time to stop producing breast milk. This also helps to reduce the pressure in the breasts.

Expressing large amounts of milk or for a long period of time signals the body that it's time to make more milk. Nipple stimulation also signals the body that it's time to make more milk.

MILK PRODUCTION CAN BE EMOTIONALLY PAINFUL

Breast milk production is often a painful reminder that there's no baby to feed. It can feel very unfair and make grief more complex. Talking to someone, whether a partner, friend, or family member, can be very helpful.

MILK PRODUCTION CAN BE PHYSICALLY PAINFUL

If breast milk is not released from the breast, the breast can become "engorged" and painful. Here are some suggestions on how to manage physical pain:

- Hand expressing small amounts of milk
- Place raw cabbage leaves in the bra
- Apply cold packs
- Drinking mint or sage tea
- Take ibuprofen or Tylenol

NOTE: If you have an allergy or sensitivity to any of the above, please do not attempt that method without first consulting your healthcare provider.

RECOGNIZING MASTITIS

Mastitis is an infection in the breast tissue when the breasts produce milk. Symptoms include:

- Fever
- Body aches
- Hard lump to breast
- Yellow nipple discharge
- Redness or pain to one breast
- Wedge-shaped redness to breast

INTERACTING WITH SOCIAL SPHERE

AN UNFORTUNATE REALITY Navigating Unhelpful Comments

People are going to say hurtful things when they learn your pregnancy did not go as planned. It's not that people mean to be hurtful, they simply don't know how to respond. One consequence of the silence of perinatal loss is that people don't have the knowledge or vocabulary to respond in a helpful way.

In this section of the booklet, you will learn how to stand up for yourself and educate those around you about how to respond in a helpful rather than hurtful way.

ASSUME THE BEST

People Truly Mean Well

As humans, we want to fix things. When someone we love is hurting, we want to fix that hurt. When we don't know how, we can make mistakes and be unhelpful in our efforts. Despite how unhelpful people's responses to your loss may be, people truly mean well. Reminding yourself that people don't know how to respond and that they mean the best isn't going to make what they say hurt less, but it's a good reminder that your social sphere has not turned against you.

THE WARNING SHOT Being Prepared for What You'll Hear

The idea behind a "warning shot" is that if you know what's coming, you can prepare yourself to receive the "blow." You've receive the first warning shot - people are going to say hurtful things. The second half of the warning shot involves examples of some of the hurtful things people may say.

EXAMPLE COMMENTS

Well Meaning Sentiments that Miss the Mark

"At least" comments:

- "At least you can try again"
- "At least you have living children"
- "At least this happened early"
- "At least you weren't far along"

Religious comments:

- "Everything happens for a reason"
- "God knew what he was doing"
- "God did this to make you stronger"

Even though people mean well, if what they are saying to you is hurtful, it's okay to let them know. There are ways to stand up for yourself and tell people they are being unhelpful. On the next page you will find examples of how to respond to insensitive comments, how to cope with insensitive comments, and how to communicate to your social circle "helpful" versus "unhelpful" ways to respond to your loss.

EDUCATE YOUR SOCIAL SPHERE

How to Advocate for Yourself

Keep in mind that your social sphere cares about you. They don't know how to respond in a helpful way. They need to be educated.

Educating Your Social Sphere



Example Social Media Post for Breaking the News



Coping with Insensitive Comments



RESPONDING TO COMMENTS

- "It hurts my feelings when you say..."
- "Please don't say things like..."
- "It's not helpful when you say..."
- "I know you don't know what to say, you don't have to say anything."

HOW TO COPE WITH INSENSITIVE COMMENTS

Balancing with the Positive

Not every word from every person you ever knew will be hurtful. While it's the hurtful comments that stand out, don't forget about the comments that weren't hurtful. Allow yourself to feel the pain from the negative comments, then reflect on some of the helpful comments. Below are some examples of how to cope with the hurtful things people might say.

Journaling

Journaling can be a helpful way to process unhelpful comments by others.

Poetry

Poetry is a powerful tool to heal. Try using the comments or the emotion(s) it provoked as a poetry prompt.

Venting

Sometimes we just need to vent. Find someone you trust and schedule a time to vent.

PARTNER RELATIONSHIP



Communicating
with Your
Partner



Communicating with a spouse or partner can be difficult when all is well. After perinatal loss, communication could be easier or harder. You may or may not know how to talk about what you're feeling or what you need.

It's important to keep communication open with your partner. Dedicate time every day or week to sit down with your partner for no reason other than to talk.

If you're finding it difficult to talk about what you're going through, or don't know how to start the conversation, scan the QR code on the left for suggestions on communicating with your partner.



Everyone
Grieves
Differently

No two people grieve the same way. Some people may wear their grief openly, others may not show their emotions. Grieving with your partner or spouse can be difficult, especially if the two of you do not grieve the same way.



Intimacy
After Loss

Intimacy is an important part of your relationship. Some, but not all, find that intimacy after loss can be very scary or very emotional.

It's important to talk about your feelings and fears about intimacy after loss. This conversation might be hard to have. You may find you would like guidance or additional support.

LIVING CHILDREN

EXPLAINING DEATH TO SIBLINGS

How to Have Tough Conversations

It's not fair to have to tell a child that their sibling will not be coming home. It can be hard to find the right words to help kids understand what's happening. There are resources available for parents. Activities such as playing games or reading books as a family are helpful ways to talk about the death of a sibling.

PLAYING GAMES

Play is the Language of Childhood

Play is how kids learn about themselves, the world, and how they feel. Playing games can be a helpful way to talk to your kids about your baby and help them process what happened. The QR code has ideas on how to use play to help your kids talk about and process what your family is experiencing.



ADDITIONAL RESOURCES

Scan the QR code for additional activities, games, and craft ideas to help children grieve.

READING BOOKS

Age Appropriate Conversations

Unfortunately, the death of a sibling is not an uncommon experience. There are a number of helpful books you can read with your kids that help explain death in an age appropriate language.

RITUALS

Including Everyone

Rituals and traditions are a big part of the human experience. Rituals are also helpful in grief and healing, no matter the age. Having a ritual your kids can be a part of can be a meaningful, healing activity for your family. Scan the QR code to see what other families have done with their kids.

COPING AFTER LOSS

LEARNING TO LIVE AGAIN

Adjusting to the New Normal

Life will never return to 'normal' after perinatal loss. Losing a baby or pregnancy changes you. That does not mean there is no hope. It is possible to learn how to live and enjoy life again. It's a long process, but it is possible.

COPING

What Does it Mean?

Coping means learning how to deal with hardship, emotions, and difficult experiences. There's no 'one right way' to cope. However, some ways of coping are healthier than others. For example, drinking alcohol in moderation is not harmful, but when used to numb or suppress feelings, it can be unhealthy. One coping mechanism may be very helpful for one person but not helpful for another. Learning how to cope after perinatal loss is a very personal experience.

QUESTIONS TO ASK YOURSELF

- "Do I find this helpful?"
- "Am I doing this to numb my feelings?"
- "Am I doing this to escape?"
- "Would I be concerned if a friend was coping this way?"
- "Do I wish I were using other ways to cope?"
- "Do I change my coping behavior when I am alone?"

HEALTHY WAYS TO COPE

- Journaling
- Blogging
- Walking
- Hiking
- Yoga
- Meditation
- Prayer
- Therapy
- Talking with friends
- Volunteering



WARNING SIGNS

- Sleeping more or less than is usual for you
- Eating more or less than is usual for you
- Using coping mechanisms in secret
- Withdrawing from others
- Thinking you don't deserve to be happy
- Feeling unable to deal with daily life
- Inability to make decisions

If you are experiencing two or more of the things listed above, consider talking to your healthcare team. There is nothing wrong with you, but you may need additional resources to understand how to live with your grief.

ASKING FOR HELP

IT'S OKAY TO NEED HELP

Asking is Not Weakness

Living in a new reality without your baby is one of the hardest things you'll ever do. It's not something you need to face alone. It's okay to 'not be okay.' It's okay to need help. It's okay to ask for help.

HOW TO ASK

Where do I Even Start?

You might know you need help but have no idea where to start. Those who love you want to help, but they don't know what to do. There are different types of support you may find helpful: Emotional, Social, and Practical. Different people help in different ways. Based on each type of support, consider who you know that would best be able to support you.

Emotional Support

Emotional support is provided by someone who sits and listens, bringing calm and peace.

Social Support

Social support is provided by someone who makes you feel like you belong.

Practical Support

Practical support is provided by things like cooking, cleaning, or picking up groceries.

GRIEF RESOURCES

Knowing Where to go for Help

Professional Community

- Individual/Group Therapy
- Family Therapy
- Support Group

Support Community

- Walking Buddy
- Childcare
- Coffee Date
- Dinner



Make a Support List

Write down the names of those who can provide
Emotional, Social, or Practical support:

Emotional

Social

Practical

MAKE YOUR NEEDS KNOWN

Here's how to ask:

Scan the QR code to read through more suggestions on how your friends and family can support you.



PREGNANCY AFTER LOSS

PREGNANCY AFTER LOSS

A Changed Perspective

The thought of becoming pregnant after loss may be terrifying. You see the world differently now that you know perinatal loss can happen to you. The decision to try to become pregnant after loss is a very personal decision. Only you can know when, or if, the time is right to try again.

WHAT TO EXPECT

An Emotional Experience

Unfortunately, pregnancy after loss is not always bliss. Sometimes it's fear and anxiety and wondering if your baby is going to survive. One woman described her pregnancy after loss in terms of fear and excitement. "Today I'm 70% scared and 30% excited."

TIMING & READINESS

For You and Your Partner

There's no magic way to know if you're ready to become pregnant after loss. The decision is uniquely personal. Your partner may or may not be ready to try for another pregnancy at the same time as you. It's important to keep communication open and respect each other's feelings, fears, and emotions.

Pregnancy after loss is an emotional as well as physical experience



Take your time making the decision about pregnancy after loss

PREVENTING PREGNANCY

If you are not breastfeeding, your body may begin ovulating 2-3 weeks after giving birth. If you do not plan on becoming pregnant right away, you will need to actively prevent pregnancy. Talk with your doctor about what method is best for you.



Pregnancy
"Conversation Starters"

NOTES:

WRITE IT DOWN

Practice Journaling

Jot things down as you think of them. Perhaps it's a feeling, a thought, or something you want to remember later. Maybe you want to play with poetry, or maybe you just want to doodle. Use this page as you see fit.

Thoughts:

Notes:



Feelings:



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