PERINATAL BEREAVEMENT FOR BIRTH PROFESSIONALS

A Handbook For Supoorting Families in Unexpected Outcomes

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To those on the front lines of birth work

who give their compassion day after day

&

To all those who navigated loss in silence

Contents

Preface

Life and death titter a fine line in the birth world. From the first flicker of the heartbeat to the first breaths; many find themselves in a situation they never expected. One in four women experience pregnancy or infant loss at some point in their life. For others that number is higher. Loss creates a deep impact on more than just the women who experience them. The effects can last months, years or sometime the rest of their life. As those on the front line working face to face with families during the perinatal period, recognize the importance of preparedness to support families during their time of need.

When a family is expecting a new baby, our instincts lean toward happiness, joy and celebration. Why wouldn't we? As a seasoned birth professional I have seen every side of birth. Some of the hardest births are the ones you were not prepared for and no one really talked about. As a society we tend to shy away from those uncomfortable conversations: the what if conversations. It is time to break the silence.

The death of a baby is a catastrophic event for anyone. We need to open the space for conversations to happen. As front line birth professionals we should talk to our clients about the subject of loss. The conversation should not be a fearful topic, but on the basis for informed decision making. Similar to how we discuss the risks of potential cesarean or GBS infection as they prepare for their journey to parenthood.

Let's create a safe space for conversations about loss.
My first daughter was born unexpectedly premature at 29 weeks. I was completely unprepared for what was to come. In the swarm of chaos the only people who gifted me with a sense of calm were the NICU nurses. They had great compassion for the experience I was going through. They went above and beyond their job titles to provide me understanding in my time of need.

Subsequent miscarriages weighed heavy on my family. One of which took place on a family vacation to universal studios. We have visited year after year as a memorial to our child who wasn't. An ultrasound revealing multiple markers for Down Syndrome left us in grief for half my fourth pregnancy.

The journey through the birth world in my personal and professional life has taught me many things regarding loss. Loss impacts us all in different ways and can resurface later in life. Just because someone did not tell you about their loss doesn't mean it did not happen or will not affect them. Families may experience a loss and need additional support with a subsequent pregnancy. Birth professional trainings and even some medical trainings lack adequate bereavement education.

In this book, BABES aims to educate birth professionals and prepare them to support families who experience different types of loss and navigating what comes after. Let's shift the philosophy about bereavement and break the silence about loss in our society.

Introduction

Many view the world of birth as full of snuggly babies, smiles, and celebration. There is another side of birth though, and many of us hope to never be a part of. The hard truth of it; we will be a part of it. As a birth professional we will encounter loss with our clients. It comes in the form of unexpected loss, support, and the lasting effects it has on both families and caregivers.

In the unfortunate circumstance your client experiences a loss, either prenatally or after birth, it is important to be aware of the grieving process and how you might be a part of it. No matter which stage of pregnancy a loss takes place, it is still a loss for a family. It can be an overwhelming and intense process that requires recovering physically, emotionally, and spiritually.

It is important for those whom experience loss to be surrounded and supported by those who understand and can empathize with each individual circumstance surrounding the loss. Parents and families need a variety of immediate and long term support to help them through the bereavement process. This includes families experiencing a preterm delivery with the potential of loss or those experiencing unexpected outcomes.

At BABES, we believe perinatal bereavement is a core skillset of a front line birth professional. This includes knowledge of loss, preterm delivery, and care of the caregiver. Theses skillsets serve to not only to help families who are currently facing an unfortunate circumstance, but to also help families who have faced similar experiences in the past and are having a subsequent baby.

**A Special Trigger Note. This handbook may be hard for some. It can be an emotional process to talk about loss especially for those who have experienced loss themselves. We encourage you to take breaks as needed and even come back at a later time. If this book brings up feelings of grief from the past or unexpected feelings reach out to your birth professional community for support.

Chapter 1

Understanding the Grieving Process

"I will not say: do not weep; for not all tears are an evil."
— J.R.R. Tolkien

What is Grief?

Grief, mourning, and bereavement are often used together when talking about loss. Sometimes they are spoken interchangeably to mean the same things, but each mean different things and play different roles in loss. They all reside within the grieving process.

Grief is the process of experiencing psychological, behavioral, social, and physical reactions to loss. Mourning is the public display of grief. Bereavement is the entire process precipitated by the loss.

To put it in less dictionary-isk terms, grief is a journey unlike any other. It often has no direction or set rules. No two people will grieve in the same way, even if grieving the same event. Grief knows no timelines, boundaries, or patterns. Our personality, support system, culture, religion, value system, and natural coping mechanisms shape our own unique grieving process.

In perinatal bereavement two categories of loss exist; physical and symbolic losses. A physical loss occurs when physical presence can be established; something tangible you can hold and see. Society often Physical recognizes this type of loss. A symbolic loss refers to the loss of something intangible; something you cannot see or touch. Intangible loss comes in many forms; disruption of health, changes in self-worth, or lost experiences. In contrast, society seldom recognizes this as a loss requiring support or guidance in the grieving process.

Women often develop a bond with their unborn babies. It is important to acknowledge that there was a mother-baby relationship before the loss can be recognized. Grieving is a healthy process where the bereaved person actively struggles with the emotional tasks facing her. This is known as grief work.

Stages of Grief

Over the years many theories or models of the grieving process appear in the world. Each include varying stages. All models have one thing in common; there is a process to grief and those experiencing it must travel through to the other side.

Support through the stages help families move from stage to stage. Some individuals will take years in one stage while others may only take weeks. Some experience stages throughout, building in intensity such as acceptance. Others may experience an ebb and flow of stages such as a high level of depression, followed by a decrease and then an increase.

The stages of grief are a framework to help explain how we typically grieve as humans. One such framework introduced in 1969 by a Swiss psychiatrist, Kubler-Ross, models a five stage process of grief. It is now widely accepted in western culture.

The 5 stages of Grief

Stage 1: Shock, Denial, Isolation

- Increasing awareness
- Emotions: sorrow-guilt-anger
- Searching
- Refusal to admit the truth of the reality occurring

Stage 2: Anger

- Strong passion or emotion of displeasure
- Blame (self or directed at other

Stage 3: Bargaining

- Turning to faith

- If only statements (had sought medical attention sooner, been a better person)
- Promises to self or others (I will be a better person if…., I will never again…. if….)
- Belief that there was something they could have done differently

Stage 4: Realization

- Depression
- Apathy
- Bodily Changes

Stage 5: Acceptance/Resolution

- Acceptance of the event
- Coping with the loss
- Mental Calmness
- Anniversary reaction

Forms of Grief

Grief comes in many forms. The experience takes place on a multi-level plane, which can include physical, emotional, and spiritual pain. Some individuals experience one form of grief while others experience many forms of grief. One cannot know how the grieving process will unfold for your clients.

Common/Normal Grief

Common or "normal" grief refers to a grief response which falls under a broad category of predictability. Though this type of grief is not a "normal" state of being.

Common grief begins soon after a loss and over time the symptoms lessen, but may not entirely fade. The initial responses often mimic a defense mechanism protecting the individual from the full impact of the news or realization. Someone may feel shock, anxiety, anger, depression, or other debilitating symptoms that affect daily activities for a period of time. Some other common experiences include:

- Crying
- Sadness
- Longing
- Loneliness
- Denial
- Disbelief
- Inability to concentrate
- Meaninglessness
- Helplessness
- Numbness
- Over-reacting
- Fear
- Shame
- Loss of appetite
- Weight Gain
- Confusion
- Loss of interest
- Fleeting hallucinatory experiences
- Withdrawal
- Avoidance

Grief represents a healthy part bereavement. A healthy grieving process contributes to balance in a woman's life and in the family. Emotional and physical hazards exist with an inability for a healthy grieving period. Research supports a woman's need for support during loss regardless of the nature of the loss or extent to which it is recognized by society. The way a woman grieves varies greatly from culture to culture.

Parents often find the loss of a baby more difficult because multiple loses occurs at once. Most parents not only grieve for the loss of a child, but also the loss of the future with that child. Parents can experience both similar and contradictory emotions, which can strengthen or strain their relationship. For some families the loss of a baby may be their first experience with death and catch them unprepared with inadequate coping techniques or support.

Men and women tend to experience similar initial grief responses, but experience differing levels of self-blame and guilt. Men and women experience different levels of bonding during pregnancy. A woman is more likely to a bond with a baby the moment she finds out she is expecting; while men tend not develop an emotional relationship with the unborn baby until they are able to see physical changes in the woman's body, sees the baby on an ultrasound or hears the baby's heartbeat. It is not uncommon for some men to not begin the bonding experience until the baby is born.

Up to a third of women experience prolonged impairment physically and mentally after a loss. Women who have experienced previous loss show higher levels of psychological distress. The process for recovery takes time. A period of 2-4 years is average, but it is not uncommon for parents to need five or more years.

Complicated/Complex Grief

Complex grief differs from "normal" grief in that it significantly impairs functionality and symptoms last for more than six months. Complex grief may impair your ability to function in a daily routine. Loss in pregnancy or shortly after birth increase the chances of parents developing complex grief. About 10-20% of families who lose a child experience this type of grief.

Those who do not have a social support system, have relationship difficulties, or do not have other children are at a greater risk for developing complex grief. Parents who have a termination of pregnancy due to fetal abnormality are at a high risk. Consistent feelings of guilt and self-blame are often associated with complicated grief. Childless women who suffer a miscarriage have significantly higher levels of grief than women who already have children.

Anticipatory Grief

An Anticipatory grief response occurs prior to an impending loss. As soon as one understands and accepts the loss of a child they begin to grieve.

This can result in expressions of sadness, sorrow, anger, crying, guilt, fatigue, poor concentration, or emotional numbness. These emotions may be just as intense as those in the grief period once the loss has occurred. Some anticipatory grief result from fear surrounding an impending loss or unexpected outcome that may not occur.

For example, a family tested for multiple markers for Down Syndrome and spend the remainder of the pregnancy in waves of anticipated grief about an uncertain outcome. Parents, family members, or even care givers can experience anticipatory grief. Knowledge of loss prior to a loss event allows families time to prepare, but increases the risk of depression. Grief felt before a loss does not lessen the impact of grief after a loss event.

Birth professionals can help by allowing parents to express their feelings in a safe environment where they will not feel judged. Give parents options about what they can do through the process. Remind parents they do have options and opportunities to make memories with their child to begin the bereavement process.

Delayed Grief

Grief symptoms experienced long after the loss or at a much later time is known as delayed grief. Greif unprocessed soon after the event may be triggered at a much later point in life and even with a subsequent pregnancy. Delayed grief is often experienced more intensely and more drawn out at this later point.

Those who experience delayed grief often put their grieving process on hold to pay attention to something they felt required more immediate care. Examples include other children in the family who needed care or feeling the need to stifle their own grief to tend to a partners.

Grief not processed does not go away on its own and can often cause physical, mental or emotional problems. For those who feel they cannot fully process their grief, for whatever reason, encourage them to take things a bit at a time. A simple yet effective tool is keeping a journal about how there are feeling and their experiences day to day.

Uncommon Grief Experiences

While grief does not follow a patter there are some not so common types of grief.

Distorted Greif: Extreme, intense, or atypical reactions to loss. May include odd behavioral changes or self-destructive actions.

Cumulative Greif: When one experiences a second loss while still grieving a first loss. Also referred to as “bereavement overload” or “grief overload”.

Chronic/Prolonged Grief: Continual extreme distress reactions from loss that do not subside. Individual becomes incapacitated by grief and cannot function in daily activities. Symptoms lasts over a long period of time and show no progress towards improvement.

Exaggerated Grief: Intensified grief reactions that may worsen over time. Characterized by extreme and excessive grief reactions possibly to include nightmares, self-destructive behaviors, drug abuse, thoughts of suicide, abnormal fears, and the development or emergence of psychiatric disorders.

Masked Grief: Grief reactions that impair normal functioning however the individual is unable to recognize these symptoms and behaviors are related to the loss. Symptoms are often masked as either physical symptoms or other maladaptive behaviors.

Traumatic Grief: Normal grief responses experienced in combination with traumatic distress suffered as a result of a loved one dying in a way perceived to be frightening, horrifying, unexpected, violent and/or traumatic. Distress is extreme enough to impair daily function.

Abbreviated Greif: A short lived grief response based on the immediate filling of someone or something else or because there was little attachment to the loss. This may occur when a family becomes pregnant again immediately following a loss.

Absent Grief: When no signs or symptoms of grief occur. Bereaved behave as though no loss occurred. This is a concerning form of grief when long lasting. This does not apply to individuals who outwardly say they are not grieving, but internally they are.

Sibling Grief

Children who experience loss may experience it differently than an adult. They may find the changes surrounding the loss confusing or difficult to get through. Children's experience of intense emotions such as loss tend to be few. They may only show grief for a short period of time, not show feelings openly, or begin to exhibit new behaviors unseen by parents in the past. Every child will experience and work through their emotions differently.

Children will be influenced by their age, personality, stage of development, previous experience or exposure to death, or how involved they were in prenatal experiences. Some children feel they did something to cause the loss or feel they might die.

Parents often find coping with a child's grief along with their own difficult. Parents should be open and honest in communicating with their older child/children about the loss. This includes taking extra time to talk about the experience, use direct language and accurate words, providing reassurance, and incorporating the child/children in planning a funeral or farewell ceremony.

It can be helpful to explain to children the families own cultural and spiritual beliefs about death in simple terms. The parents should try to keep as normal of a routine as possible for the child. They should make sure the child does not feel at fault and help the child talk though their anxieties or fears. Children at different stages of development have different understandings of death and the rituals that surround death.

Age	Understanding of Death	Expression of Grief
Infant to 2 years	• Does not recognize death • Exhibits behaviors related to separation	• Quiet, sluggish, poor sleep, unresponsive, weight loss
2 to 6 years	• Confuses death and sleeping • May think it is temporary, reversible • May believe thoughts can cause another to be sick or die	• Problems with eating, sleeping, bladder/bowel control, tantrums • Asks many questions
6 to 9 years	• Believes death is a person or spirit (skeletons, ghosts, bogeyman) • Death is final and frightening but happens only to others	• May ask specific questions about death process • Problems with aggressiveness, acting out, clinging, destructive and/or antisocial behaviors • Feelings of abandonment
9 and older	• Knowledge that all will die and it is not punishment • Death is final and cannot be changed	• Heightened emotions of guilt, anger, shame • Anxiety about own death

		• Problems with eating and sleeping • Impulsive, regressive behaviors • Fear of rejection

The Six R Process of Mourning

A popular theory about processing grief is Dr. Therese Rando's Six R's of Mourning. According to her research the bereaved go through six emotional states through their grief journey. The six R's are:

- Recognize the loss
- React to the separation
- Recollect and re-experience
- Relinquish old attachments
- Readjust
- Reinvest

According to Rando, parents face a series of obstacles in this mourning process after the loss of a child.

- Parents have difficulty recognizing the loss.
- Parents have difficulty reacting to the separation
- Recollecting and re-experiencing the loss because there is little experience to remember
- Parents are compromised in their ability to readjust to the new world without forgetting the new one
- Parents have difficulty reinvesting in a similar relationship

Societal Factors in Loss

Society and culture have a big impact on mental health including the grieving process. There is a misconception about healthy lifestyle and good medical care guaranteeing a healthy pregnancy and outcome. This often contributes to a woman's sense of failure and self-blame if a loss occurs. Society has unrealistic expectations about grief; not only on those who are grieving, but also on those who are around those who are grieving.

Many emotions and behaviors associated with the grieving process may be uncomfortable for others to be around. It is not widely taught how to support someone who is experiencing feelings such as emotional exhaustion, anger, sadness, or guilt. It can cause those grieving to withdrawal from social setting in order to not burden others or receive unwanted solicitation or advice. Religious beliefs or practices may be minimalized or seen as an option-less decision.

Unfortunately socioeconomic status plays a role in views of others losses. Those who are on a level socioeconomic may experience more criticism than those of a higher status. Some families may not be able to take time off of work as it would create a financial burden for the family.

A grief researcher, Ken Doka, defined a type of grief created by societal impact called disenfranchised grief. Disenfranchised grief occurs when the impact of the loss is not recognized, openly acknowledged, socially validated or publicly mourned.

This type of grief happens for one of more of the following reasons:

1. The loss isn't seen as worthy of grief (ex. non-death losses)
2. The relationship is stigmatized (ex. Partner became pregnant in an extramarital affair)
3. The mechanism of death is stigmatized (ex. Medical abortion)
4. The person grieving is not recognized as a griever (ex. Caregiver, friend,)
5. The way someone is grieving is stigmatized. (ex. the absence of an outward grief response or extreme grief responses)

Those at a higher risk for this type of grief include those with non-traditional relationships, those who socially isolate themselves, those who are socially and/or psycho-socially disadvantage such as those in a domestic abuse situation or single parents, or those who deny themselves the right to grieve. Those experiencing disenfranchised grief are not able to overcome their suffering and often have trouble returning to daily life without considerable support to overcome their grief.

Other Types of Loss and Grief

Loss and grief for parents may not always come with the death of a baby. The loss and grief may be related to the experience of labor, unexpected disabilities, birthed a boy but had expected a girl, a transfer to the NICU, or the inability to birth in the water. Some losses may be physical while others are intangible feelings or experiences.

Families often experience other losses they grieve when they lose a child. Some of the other things families grieve for when a baby dies:

- The baby they planned for
- What it would be like to be a parent
- Changes in relationship dynamics between parents
- Status in social circles
- Plans for future pregnancies
- Level of self-esteem
- Loss of interactions with other family members or children of friends
- Feelings of loss of control

Babies with Disabilities or Birth Defects

Parent's reaction to the news of a baby with disabilities will involve grief. This is especially true if the disability was unexpected. There are more than 4,000 different kinds of birth defects. For various reasons a baby may be born with a disability, which may or not be anticipated. Disabilities vary hugely in severity and their implications for the baby.

Some woman may have to adjust to the possibility of their baby dying while other conditions may permit the continuation of a healthy life. Birth defects affect one in 33 babies (about 3%) born in the United States every year.

Some women choose to pursue testing to determine many common fetal abnormalities with non-invasive screening such as maternal blood screening, nuchal translucency and ultrasound. Other invasive diagnostic tests include chorionic villus sampling and amniocentesis. Positive screening results does not always mean a baby will be born with a birth defect. Further genetic testing can be done for a more accurate result.

The process of grieving may last the same amount of time as those who have experienced a loss. It includes the loss of an anticipated future with the child. There may be an increased level of guilt and self-blame from the mother who may think she somehow caused the baby to have a birth defect. Some families will not know about a birth defect until the birth of the baby and not have time to prepare in any way for how life may be different due to a child with a birth defect or disability.

The Birth Experience

Birth is a huge life event. Families often spend months of planning. Just like any other major event, if things do not go exactly as planned families are often left with the grief of the anticipated experience. This form of grief and loss is not typically recognized in society, especially if they baby is born healthy.

A family may have planned an uncomplicated birth, even some of the more common interventions may leave her feeling like a failure. The family may have planned an experience in a freestanding birth center and then needed to transport to a hospital. A family may have been told they were expecting a boy and a girl is born. These are all still a forms of loss and parents should be encouraged to grieve.

Greif from Infertility

Infertility is defined as the inability to conceive naturally after a period of one year or unable to bring a child to term for a period of one year with regular unprotected sex. It can also define someone who is biologically unable to contribute to conception such as those with specific genetic disorders or ovulation disorders. According to the Department of Health and Human Services, USA, approximately 10% to 15% of couples in the USA are infertile. About 20% of infertility are due to a problem in the man while 40-50% are problems related to the female.

Risk factors for infertility include:

- Age
- Smoking
- Alcohol consumption

- Being obese or overweight
- Eating disorders
- Vegan diet (due to inadequate vitamin and mineral consumption)
- Over-exercising
- Not exercising
- Sexually transmitted infections (STI's)
- Exposure to some chemicals
- Mental Stress

Grief related to fertility can be repeated again and again with each failed attempt or loss of pregnancy/stillbirth. Parents may be triggered by outside factors such as societal pressure (you are already 30 why don't you have any kids yet?), other friends or family being able to conceive, anniversary dates of previous losses. The grief process is similar to other forms of loss even if the parents have never experience the death of a baby.

Why Grieving is Important

Acknowledgement of emotions and the grieving process must be done in order to release those emotions. Emotions that are not regularly released are stored in our bodies. These stored emotions created the production of stress hormones and can create illness, disease, bodily imbalances, pose serious health risks, and contribute to infertility. In some cases extreme emotional stress can cause heart problems.

Some of the physical symptoms of grief include:

- Aches and pains
- Chest pain
- Digestive problems
- Fatigue
- Feelings of heaviness
- Headaches
- Insomnia
- Loss of appetite
- Sore muscles
- Weakness
- Dry mouth
- Shortness of breath
- Disorientation
- Listlessness
- Dizziness

Physical symptoms of grief may in turn contribute to other grief complications such as social isolation and loss of ability to perform day to day activities. Grieving is needed to be healthy.

Birth professionals can help counsel families in how to care for themselves during the grieving process to avoid physical symptoms of grief from effecting their daily lives.

Impact on Bonding in Future Pregnancies

Not all women feel a strong bond to their baby during pregnancy. This is normal, but not something widely accepted in western society. For a woman who has experienced a previous loss or multiple losses, bonding during pregnancy can be even more difficult. Many families experience fear surrounding the idea of getting attached to a baby they may lose again. The family may not have had the chance to properly grieve for their previous loss/es.

The partner's reaction to the pregnancy can be a barrier for the mother in bonding if the reaction is not what the mother was expecting. The partner may feel less excited than with a previous pregnancy which can influence how the mother feels about this pregnancy. Other feelings such as the couple does not deserve the baby or that this baby will not be as good as the last one would have been can also impact bonding in pregnancy.

A previous loss can make it hard to have positive thoughts about the pregnancy which can delay bonding. Reaching the same gestation as a loss occurred can trigger significant negative feelings or anxiety for a mother and partner. Mood disorders such a prenatal depression can impact bonding.

Bonding during pregnancy has many benefits for the health of mother and baby. The bond between mother and baby during pregnancy impacts the bond she will have with her newborn. This can affect the baby's future growth and development. A strong bond between mother and baby is linked to better developmental outcomes later in life.

As a front line birth professional you can help the couple establish a bond with their baby and also explain that if they do not feel one right now that is okay. Women should not be shamed or made to feel guilty because of the level of bonding they feel with their unborn child. One of the biggest ways to encourage bonding is education about pregnancy and what stage the baby is at. Knowing how their baby is growing and the different activities the baby begins to do at what time can help create an image of their baby.

Here are some activities women and families can do to help encourage a bond between them and the unborn baby during pregnancy.

- Spend time talking to the baby
- Maternal massage (the mother or partner rubs her belly or responds to kicks with touch)
- Making sure to get adequate nutrition for baby
- Journaling about the experience
- Taking pictures of the belly
- Having a mother blessing ceremony
- Taking long warm baths and watching the baby move inside the womb
- Listen to baby's heartbeat
- Take prenatal yoga
- Have partner go to yoga too
- Have partner go to prenatal appointments

Chapter

Forms of Loss

"You care so much you feel as though you will bleed to death with the pain of it."

— J.K. Rowling

Addressing Loss

One should be careful when dealing with loss and bereavement not to make assumptions. It is impossible to understand how much significance another person has to their pregnancy or baby. Childbearing carries a vast range of feelings and beliefs including unspoken hopes and expectations based on personal and cultural values. We need to accept grief in childbearing, like pain, is what the person who is going through it says it is. Each family experiences loss differently and has different feelings about the pregnancy.

Factors to consider; how long it took the couple to get pregnant, if they struggled to get pregnant, or if they needed to use medical assistance to get pregnant. Families place differing forms of importance on a pregnancy ranging from continuing the family name to a social fulfilment. The pregnancy may have been planned, unintended, or undesired. Families also define life and pregnancy at different times; life from conception, the potential to be a child, or a defined point in between. Feelings may be based on cultural, religious, or family traditions and each parent may not feel the same as the other.

Early Pregnancy Loss

Early pregnancy loss can occur for a variety of different reasons ranging from ectopic pregnancy to spontaneous abortion. Spontaneous abortion is the medical term for a miscarriage. The word 'abortion' is better avoided in this context, because it carries the inference of intentional action taken to end pregnancy. For most the idea of intentional is unacceptable to a grieving mother. The term 'miscarriage' is the preferred word that includes all accidental losses.

Medically, an early pregnancy loss is a loss that occurs before 20 weeks gestation though most losses in early pregnancy occur before 13 weeks. Most often a loss occurs because of a problem with the development of the baby or placenta.

Types of Early Pregnancy Loss

Threatened Miscarriage: Occurs when symptoms of miscarriage take place such as bleeding and/or cramping, but no miscarriage has taken place. If an exam is done the cervix is shown to be closed. A miscarriage may or may not follow a threatened miscarriage. Around 50% of women who experience these symptoms will go on to have full term babies.

Inevitable Miscarriage: Occurs when symptoms of miscarriage take place such as bleeding, cramping, and/or passing of tissue. An exam would reveal an open cervix meaning a high likelihood of miscarriage.

Incomplete Miscarriage: This type of miscarriage may occur if a miscarriage has or is taking place but small parts of the baby or placenta and not expelled from the uterus. This often requires medical treatment with a D&C (dilation and curettage) where what remains in the uterus are manually removed. If an incomplete miscarriage is not treated and does not resolve on its own life threatened infections can occur.

Missed Miscarriage: This occurs when, through ultrasound, it is found the fetus no longer has a heartbeat, but remains inside the uterus with no symptoms of miscarriage. A miscarriage can take place naturally but may take several weeks. Some women request medication to start the miscarriage process or elect for a D&C procedure.

Complete/Natural Miscarriage: A miscarriage where all the products of conception are naturally expelled from the body.

Blighted Ovum: This occurs when a placenta develops producing the pregnancy hormones, but due to an abnormality with the egg the fetus does not develop or failed earlier than the first six weeks. An ultrasound is only able to detect a gestational sac. A miscarriage can take place naturally but may take several weeks. Some women request medication to start the miscarriage process or elect for a D&C procedure. If a natural miscarriage does not occur medical intervention will need to take place.

Ectopic or Tubal Pregnancy: This occurs when a fertilized egg attaches itself to a fallopian tube or some other place inside the abdomen. This type of pregnancy is not compatible with life for the fetus and could put the mother's life in danger. The top three symptoms of an ectopic pregnancy include abdominal pain, absence of menstrual period, and vaginal bleeding. This type of pregnancy occurs in around 1-2% of pregnancies. Sometimes medications may be used to dissolve the pregnancy, but surgery may be required.

Chemical Pregnancy: This occurs when a loss occurs shortly after implantation with confirmed higher levels of hCG, but before an ultrasound can detect a fetus. These types of pregnancy are most commonly detected in those going through IVF treatments who need close monitoring close to ovulation. Most of these type of pregnancies go unknown and may occur before a missed menstrual cycle.

Molar Pregnancy: This type of pregnancy occurs when an abnormality of the placenta takes place, caused by a problem when the egg and sperm join. It causes abnormal tissue to grow in the uterus with or without the presence of a developing embryo. The placental cell growth is rapid compared to normal growth and has a cluster like appearance.

There are two types of molar pregnancy; complete and partial. A complete molar pregnancy only has placental parts that produce hCG, but no developing fetus. A partial molar pregnancy contains both abnormal placental cell growth and a developing embryo. This embryo most often has severe birth defects. This pregnancy is not compatible with life, because the fetus will be overcome by the rapid and abnormal cell growth of the placenta.

While the causes of miscarriage are not always known or understood possible causes of miscarriage can include:

Chromosomal Abnormalities: Chromosome abnormalities typically occur as a result of errors in one, or more, of the following: cell division, maternal age, or environment. Examples include hormonal disturbances, exposure to radiation, chemicals, or pollution, or random error in cell division.

- Smoking, alcohol and drug
- Fertilization problems
- Blood Clotting Disorders (may or may not be hereditary)
    - Factor V Leiden
    - Factor II (two)
    - Protein C deficiency
    - Protein S deficiency
    - Antithromin deficiency

  - Factor II G20210A prothrombin
  - MTHFR
  - homocysteine

Maternal health (infections, problems with uterus or cervix). The following infections can increase the risk of miscarriage:

- Bacterial vaginosis
- Chlamydia
- Foodborne infections (uncooked foods)
- Toxoplasmosis
- Parvovirus B19
- Rubella

The following uterine or cervical abnormalities may contribute to miscarriage:

- DES daughters
- Septate uterus
- Unicornuate uterus
- Bicornuate uterus
- Asherman's Syndrome
- Incompetent or insufficient cervix
- Fibroids
- Polyps

The following maternal illnesses increase the risk of miscarriage:

- Cancer, Diabetes, Lupus
- High Blood Pressure
- Kidney disease
- Luteal phase defect
- PCOS
- Thyroid disease
- Immunological problems
  - Antiphospholipid syndrome (APS)
  - Antinuclear antibodies (ANA)
  - Human leukocyte antigens
  - Natural killer cell
- Obesity and anorexia
- Hormonal imbalances
- Celiac disease
- Hyperprolactinemia

Termination of Pregnancy (TOP)

We talk about TOP in the early pregnancy loss section for a number of reasons. While some TOP are elective for personal reasons, many others take place for medical reasons relating to the health of mother and baby.

When we refer to the grieving process of TOP in this instance we are only talking about the experience of grief following a TOP for fetal abnormality and the guilt following TOP. Some conflicting emotions which impede the grieving process include:

- The pregnancy was probably wanted
- The TOP is a serious event in both physical and social terms
- The reason for TOP may arouse guilty feelings
- The recurrence risk may constitute a future threat
- The woman's biological clock is ticking away
- Her failure to achieve a 'normal' outcome may cause guilty feelings

Considerations for early loss

For many women a positive pregnancy test can be the beginning of their relationship with their pregnancy. When a loss occurs early in pregnancy it can bring up a particular set of circumstances. There may be confusion about if she was pregnant in the first place. She may not feel comfortable sharing the loss based on how early the loss occurred. Often time the gender of the baby is unknown and there is often no physical comments of baby to form tangible memories with. Families are often left with the lingering questions of "Why?" and may never receive an official answer.

Perinatal Loss

Perinatal loss includes loss by stillbirth and the baby dying in the first week. A stillborn is the delivery of a baby who has died and is greater than 20 weeks gestation. For about half of stillbirths, the cause may be detected by testing after the birth. For many others the reason remains unknown.

A study showed mothers recover from the loss of a stillborn better if she is able to decide how long to keep the baby with her after the birth and if she keeps birth mementoes. Mothers who had the hardest time recovering were those who had a delay of the birth after fetal demise was detected.

Early Neonatal Death

A neonatal loss is the death of a baby who was born alive and died within seven days of birth. The length of life may be days, hours, or minutes. Grieving a live born baby who dies may be helped by three factors: the mother has seen and held her baby; giving her genuine memories, a registration of both the birth and death of the baby dying neonatally; which provides evidence of the baby's life, and investment of caregivers in the care of the dying baby.

The most common causes of neonatal death are premature birth, low birth weight, and birth defects. Premature birth and low birthweight cause about 1 in 4 neonatal deaths (25 percent). Birth defects cause about 1 in 5 neonatal deaths (20 percent). Other causes of neonatal death include problems in pregnancy such a preeclampsia, problems with the placenta, umbilical cord and amniotic sac, infections like sepsis and asphyxia.

Premature babies are more likely to die short after birth than full term babies because they are at higher risk for developing serious complications such as respiratory distress syndrome, intraventricular hemorrhage, necrotizing enterocolitis and infections. The most common birth defects leading to neonatal death include heart defects, lung defects, genetic conditions, and brain conditions.

Loss Statistics

Approximately, 40% of pregnancies end in miscarriage every year in the United States. Most miscarriages happen in the first trimester of pregnancy. Second-trimester miscarriage happens in 1 to 5 out of 100 pregnancies (1 to 5 percent) between 13 and 19 weeks.

The National Center for Health Statistics (NCHS), estimates that there are more than 1 million fetal losses per year in the United States, with the vast majority of these occurring before 20 weeks of gestation. A total of 23,595 fetal deaths at 20 weeks of gestation or more were reported in the United States in 2013.

The U.S. fetal mortality rate was 5.96 fetal deaths at 20 weeks of gestation or more per 1,000 live births and fetal deaths. In 2013, the fetal mortality rate for non-Hispanic black women (10.53) was more than twice the rate for non-Hispanic white women (4.88).

About 1 pregnancy in 100 at 20 weeks of pregnancy and later is affected by stillbirth, and each year about 24,000 babies are stillborn in the United States. About 30% of fetal deaths are of unknown causes and nearly 30% relating to placental, cord and membrane complications.

Preterm birth rates continue to increase while overall birth rates decline in women under the age of 30. The number of fetal losses continues to increase over time. The fetal loss statistics reported above do not include elective abortions.

Chapter

Birth Professionals in the World of Perinatal Bereavement

"Grief can be a burden, but also an anchor. You get used to the weight, how it holds you in place."
— Sarah Dessen

Looking For Support

As a front line birth professional you are a caregiver. Clients and families look to us for our expertise and our support. They look to us as a part of their vision in their journey to parenthood. Many times our clients surround our skillset with an air of mystic and even magic as if we have powers to make all their dreams possible.

When things do not go as planned our presence shifts into the unknown. For those without knowledge of bereavement and loss our roles become less certain. As caregivers our heart aches for our clients in their time of need. We search for a way to help and to ease their pain.

The new role one takes on has been called different things. Some call it companioning and other refer to it as a bereavement doula or a bereavement specialist. No matter what you call it, this is the role we must take on as birth professionals in order to support our clients in their time of need. Our first step is to learn more about ourselves.

Owning Your Own Beliefs

Before we are able to be of service to others we must first know ourselves. Much like our responsibilities as doulas we must take a neutral stance with our clients regardless of our own beliefs. If we are not able to do this we place our own beliefs ahead of our clients and risk imposing our own bias upon them. The idea is not to discard our own beliefs, but have the ability to leave our own experiences at the door.

Take some time to write out the answer to the following questions:

- What are your own experiences surrounding loss, grief and death?
- What associations does the culture or religion you are a part of say about these subjects?
- What preconceived notions do you have about things?
- How will your beliefs potentially impact a client and family during a period of loss?

Regardless of past experiences, preconceived notions, and stories from others it is important to keep some key concepts in mind.

- Birth Professionals grieve the loss of their clients and it is okay
- Let go of expectations
- Sometimes we don't have an answer
- Know your own fears about death
- It is okay to just be present even if you're not "doing" anything
- We cannot assume the level of our client's grief
- We cannot fix or take away the pain of loss
- Rely on your instincts and intuition

Roles in a Bereavement Scenario

As front line birth professionals we all have different roles to play in a bereavement scenario. Ultimately we are all working towards the same outcome so we should always seek to work cooperatively with one another. One-on-one sensitive and compassionate caregiving is the primary objective to support families. With all the scenarios that could take place it is hard to determine ahead of time what professionals will be involved. Some roles include:

Doctor/Midwife

A client's primary medical provider is often the one with the longest standing relationship with a client and can provide consistency in care long after the loss has occurred.

A primary medical care provider may be the first point of contact during a period of loss. A medical provider may not be able to spend a considerable amount of time with a client if they have other families in their care.

As with any caregiver they may be experiencing their own personal grief or feelings of responsibility depending on the circumstances. The client may have feelings of anger or disappointment towards their medical provider. In this case it may be difficult for the provider to offer needed support. A midwife will need to transfer care to a hospital maternity provider since fetal demise is out of scope for their low risk care.

Chaplain

Chaplains are made available at hospitals for families and individuals at all times regardless of spiritual beliefs. Chaplains often do not have specific knowledge of the world of birth. They may offer comfort to families who seek answers to "Why". Some families see this as another stranger in their already chaotic event and do not find comfort in having a chaplain present.

Social Worker

Hospitals have social workers on staff to assist families during a time of loss. Perinatal social workers are sometimes staffed in the hospital to work specifically with families during the childbearing years. In the event of a loss, perinatal social worker helps families to understand, express, and cope with feelings of grief and assists as they learn to live with their "new normal. Families can find comfort in their expertise.

Nurses

Nurses are an integrate part of a care team. They are present at a hospital 24/7 for needed care. They are often the ones who assist parents in interacting with a lost child and explain aspects of death protocols. Often nurses spend more time with a client than their primary care provider in the event of a stillbirth or third trimester loss. They offer physical and emotional support to the best of their abilities.

Doula

A doula is a labor support professional hired by the client. During a period of bereavement they offer similar services to the birth doula with information, physical support, and emotional support. A doula can be there to help a family from beginning to end. Clients already have a trusting relationship with their doula. If a doula has not been educated in bereavement they may have to rely heavier on the cues of the other professionals present.

Birth Photographer

A birth photographer is a photographer hired by the client to capture the birth story. They are often trained doulas as well as photographers. During a period of bereavement they can offer their services of photography. If they do not feel comfortable editing the photos, professional organizations such as Now I Lay Me Down To Sleep offers editing services free of charge. If a photographer has not been educated in bereavement they may have to rely heavier on the cues of the other professionals present.

How Doulas Can Help

Some families may choose to hire you as a doula to assist them with a known loss. In this case they would provide many of the same things as a birth doula including physical, informational, and emotional support. They would help educate the family on what is expected and what their options are. For some families a doulas presence brings a sense of validation to the situation that they are still having a baby even if they may be born stillborn or not live long after birth. Some families just want someone else there to go through the experience with them so they are not alone.

If you are a doula for a family that has experienced a loss in the past and are having a subsequent child you are there to guide them through what may be an overwhelming experience for them. Many families have grief and fear that surrounds a subsequent pregnancy and birth. These babies are often referred to as rainbow babies. A client's previous experience may have a deep impact on the choices they make for a subsequent birth including refusal to have a hospital birth or refusing specific procedures.

The family may use this birth as a way not only to celebrate a new baby, but to also honor the baby/ies that they lost. If you are familiar with the processes of loss you will be better equipped to assist and understand the clients on a deeper level. Many families do not want to talk about their losses or the details of their loss. It can be helpful for families to know that you have been educated in loss and bereavement. It can be reassuring for them to know you understand the experienced even if they do not wish to share the details with you.

If you are a doula for a family that experiences an unexpected outcome during pregnancy, labor, or shortly after birth the knowledge of the things you will learned in this book will be helpful to the family. You will be able to give them options and potentially give them memories they will be able to have with them for the rest of their lives. You may also give them valuable time they may not have otherwise been able to spend with bonding with their baby had they not made a plan with you regarding unexpected situations.

Much of what a doula does is offering support, acknowledgement, and judgement free care. Many families will have never experienced a loss and will not know they have options. Learn as much as you can about your state laws regarding stillbirth and specific hospital policies that are local to you so you can have the information on hand for families.

Universal Compassionate Care

No matter what role you have in the birth team, there are some universal standards of compassionate care anyone can provide. Regardless of the situation providers and caregivers should always practice client-centered care, informed consent about any procedures and evidence-based practices. This may require medical providers to take extra time to explain things thoroughly so parents understand the process.

When possible caregivers should attempt to form trusting relationships with clients. Any background information such as their history, current situation regarding the loss, family dynamics, culture, and religion are all helpful information. Trust can also be established with active listening.

Hospital procedures and information verification is often repetitive and tedious on a normal day let alone a day in which a loss is or has taken place. Caregivers can ease this burden by communication with other staff to limit the family needing to repeat information and paper work during their time in the hospital.

Some other universal actions studies have found helpful include:

- Being mentally present and
- Allow parents to take their time
- Make eye contact
- Display open posture
- Convey calm unrushed demeanor

- Allow silence when appropriate
- Be sincere, genuine
- Avoid use of clichés
- Encourage bonding and memories
- Optimize immediate interaction with parents

Chapter

Loss by Trimester

"Any woman who'd ever lost a child knew of the hollowness that remained within the soul."
— Brittainy C. Cherry

Considerations

Birth in the first, second, and third trimester are very different from one another. The appearance and expectations of labor and birth change dramatically. No matter the trimester, a loss is still a loss.

Values, culture, socio-economic status, and background play a role in how the family view loss. A birth professional should exercise cultural competency with all clients.

First Trimester Loss

Any loss prior to 13 weeks would be in the first trimester and is called a miscarriage. The process of miscarriage usually begins with menstrual like cramps, abdominal pain, and bleeding. Not all women experience cramping or abdominal pain with the bleeding from a miscarriage. For some women, the symptoms will be mild and for others the experience will be more intense. Some women experience the loss of other pregnancy symptoms such as loss of morning sickness and loss of breast tenderness as a first sign of miscarriage while for others pregnancy symptoms may linger a short while after the contents of the uterus has been expelled.

The contents being expelled may contain pieces of the uterine wall, blood clots, pieces of the placenta, and the baby. Depending on what week gestation the loss occurs, the fetus may or may not be distinguishable from other products expelled. The placenta may detach from the uterine wall and come before the baby, along with the baby or after the baby. Along with period cramps and abdominal pain some women experience lower back pain. These symptoms of miscarriage may occur at once until the contents of the uterus is fully expelled or may start and stop for periods of time including minutes, hours or days before they resume.

There tends to be a blending of labor stages during a first trimester loss, but dilation and effacement do take place. Dilation often does not progress past a few centimeters. It is likely there will not be the ability to hold the fetus depending on what gestation the baby was at the time of loss. After the birth postpartum bleeding will occur, but will not last as long as a loss in further trimesters (3-10 days). Postpartum hemorrhage is still a risk for a first trimester loss.

Second Trimester Loss

A loss in the second trimester is a loss from 13 weeks to 27 weeks gestation. In the second trimester about 2-3% of pregnancies will be lost and this drops to 0.5% at 20 weeks. A loss at 20 weeks or more is considered a stillbirth while a loss prior to 20 weeks is considered a miscarriage. Losses in the second trimester can be the result of very preterm labor or the death of the fetus.

Labor may start as the response to a drop in pregnancy hormones, as a result of a physical inability to carry the fetus such as an incompetent cervix, infection, or abdominal trauma or because of fetal chromosomal abnormalities.
A loss in the early second trimester is similar to a loss in the first trimester with the exception that the fetus will be further developed. Since the size of the fetus and uterus are larger than in the first trimester cramping, bleeding, and contractions will likely be more intense and stronger than a first trimester loss, but not as strong as a full term birth.

Some women will notice a decrease in pregnancy symptoms or decreased fetal movement as their first sign of a loss, but most women less than 20 weeks will experience their first sign of loss being cramping, bleeding, or an ultrasound that detects no fetal heartbeat. If a detection of the loss of heartbeat is the woman's first sign of loss they may elect for medical assistance such as induction, D&C, or cesarean at this point. The following symptoms can be a signs of preterm labor and client should contact medical care provider immediately:

- Period like cramping with or without pain
- Abdominal pain, Lower back pain
- Bleeding
- Flu like symptoms (diarrhea, nausea, vomiting, overall feeling of being unwell)
- Pelvic pressure or lower belly
- Water breaks
- Change in vaginal discharge (watery, mucus or bloody) or more vaginal discharge than usual
- Regular or frequent contractions that make the belly tight with or without pain

The contents expelled from the uterus will include blood clots, larger pieces of the uterine wall, pieces of the placenta or the whole placenta, and the baby. The baby is clearly distinguishable from the other contents of the uterus. The baby is more likely to come before the placenta and a visible umbilical cord is likely to be able to be detected attached to the placenta. Depending on how long after the death of the fetus the contents of the uterus is expelled could affect the appearance of the fetus.

Depending on gestation, the fetus will have different levels of bone ossification, which generally begins at around 17 weeks gestation. This means many babies will not have hard bones and can be easily damaged during the loss. In an early second trimester loss it may be a good option to allow the baby to be placed in a shallow dish of water to preserve its physical form for the most amount of time. At 20 weeks the baby will be fully formed and about the size of your hand. The skin may be peeling off and appear bright red. The parents should have the option to hold their baby immediately.

The delivery of the placenta will likely occur after the baby has come, but may be met with an increased risk of complication such as postpartum hemorrhage and manual removal. Mothers may or may not produce colostrum and mature milk. Postpartum recovery will involve transition bleeding and hormonal changes which may or may not last the usual six weeks of a full term birth.

Third Trimester Loss

A loss in the third trimester occurs in about 1% of all pregnancies. Unlike losses in previous trimesters the typical first sign of a loss in the third trimester is a lack of fetal movement. A lack of fetal heart beat may then be detected by ultrasound. Some women may choose to have medical assistance such as an induction or surgery to remove the contents of the uterus at this point.

A woman may go into labor as the first sign of a loss with the detection of a lack of fetal heart beat in early labor. Prodromal labor may be experienced for days. Some women may go into labor with the detection of a fetal heart beat and sometime during the labor process the baby's heart may stop beating. The same stages of dilation and effacement occur as in a full term live birth though the labor may be more painful and need more intervention since the baby is not an active participant in labor. This may prolong labor.

There is an increase in complications with delivery of the placenta in cases of stillbirth such as postpartum hemorrhage and manual removal of the placenta. Parents will have the option to receive the baby immediately after birth. The mother will produce colostrum and mature milk after the birth. She will also transition with postpartum bleeding and hormone changes just as she would with a full term live birth.

Fatal Diagnosis & Fetal Abnormalities

In the modern era, more than ever before, we have the ability to detect fetal abnormalities. Knowing ahead of time does not always mean the outcome will change or be better. Many families face an impossible choices after a fatal diagnosis; continue the pregnancy or terminate.

Studies show about 40 percent of families faced with a terminal prenatal diagnosis decide to continue with the pregnancy. Friends and family may not understand the choice to continue a pregnancy with the prior knowledge the baby will die. Some families make their choice based on a religious preference or because they would like to spend as much time with the baby as they can.

A birth plan should be considered. Some routine hospital procedures can be foregone in an effort to maximize time with the baby. Decisions regarding sustaining life can be made in advance. Do the parents desire aggressive measures to be taken to keep baby alive? If parents are able to take the child home what support systems will be in place for the family. If the choice to discontinue life support arises what will the care plan be?

A front line birth professional can support a family through their options. They can offer understanding, validation, and education through this process. Parents may choose ahead of time to hire a bereavement doula and a birth photographer.

Front line birth professionals should create a referral list of providers if they do not offer services themselves. It should include bereavement doulas, birth photographers, bereavement councilors, and hospitals with appropriate NICU levels.

Chapter

Planning for Birth

"Just because we lost a life, doesn't mean we have to lose ourselves."
— **Nathalie Himmelrich**

Options by Trimester

In this section we talk about different options families have if time is available. They can decide what kind of birth they would like to have. This may happen if the family discovers the death of a baby prior to the onset of labor or if the family has chosen to end a pregnancy due to maternal health risk or fetal complication not compatible with life.

Doulas can help guide them through their options and what decisions can be made ahead of time. This is something that should be discussed with all clients during a prenatal meeting in the event of an unexpected loss. It can be a hard subject to speak with clients about while they are pregnant and not wanting to think about the "What ifs" of a loss, but it can help save them valuable time in the event of an unexpected loss.

First Trimester

Loss of fetal heart beat

Once a loss of fetal heart beat is detected a client may choose to let the body naturally go into labor or naturally miscarry. Other women may choose to have medical assistants in the form of medication for an artificial induction. A client may be able to choose if they want to deliver at home or in the hospital depending on the method of delivery. This is dependent on a variety of factors including gestation, provider, previous medical history, and hospital policies. A family can choose a surgical procedure such as a D&C to assist in delivery.

Termination of pregnancy

Families may choose a medical abortion with medication or a surgical procedure in this case. Families need a surgical abortion if a medical abortion fails.

Ectopic pregnancy

In the event of a found ectopic pregnancy, the pregnancy is encourage to be terminated as soon as possible. The life of the mother is at risk and the fetus would not be able to grow to term. If an ectopic pregnancy is discovered early, medication can be given to dissolve the pregnancy. In other situations surgery is needed to remove the fetus or if the medication was not successful. In rare cases the entire fallopian tube must be removed.

Second Trimester

Loss of fetal heart beat

The detection of a loss of fetal heart beat in the second trimester offers the same choices of a first trimester loss. They can wait for nature to continue the process or opt for medical intervention.

The greater the gestation the more likely a hospital delivery will be required. A family may also choose to have a surgical procedure such as a D&C or D& E to assist in delivery. Families will be able to decide what options they would like to utilize such as photography and funeral arrangements.

Termination of pregnancy

Families may choose a medical abortion with medication or a surgical procedure in this case. Families may have to have a surgical abortion performed if a medical abortion fails. Termination in late second term may have restrictions in some states.

Preterm labor

Depending on what gestation the baby is when a client gos into preterm labor will determine what kind of options are available. Some medications available, attempt to stop preterm labor which usually includes some form of bedrest. Prior to viability most hospitals will not offer any extraordinary measures to keep baby alive such as putting the baby on machines to help them breath.

Each hospital has their own definition of what they consider viable. Typically 23 weeks gestation is what week a baby is considered viable. At this gestation there is a survival rate of 20-35% and an increase to 50-70% survival at 24 and 25 weeks gestation. The survival rate for 26-27 weeks is more than 90%, but it is rare for a baby weighing 500g to survive. Families can work out a birth plan that includes what measures families are comfortable taking and which ones they are not.

Third Trimester

Loss of fetal heart beat

Options are similar to a loss of fetal heart tones in previous trimesters. The greater the gestation the more likely a hospital delivery will be required. A baby who is not alive is more likely to cause complications needing medical intervention.

Termination of pregnancy

Termination of pregnancy in the third trimester varies from state to state. Families may choose a medical abortion with medication or a surgical procedure in this case. Families may have to have a surgical abortion performed if a medical abortion fails. Families may need to

Preterm labor

Depending on what gestation the baby is when you go into preterm labor will determine what kind of options are available to clients.

There are some medications given to attempt to stop preterm labor which usually includes bedrest. Families can work out a birth plan that includes what measures families are comfortable taking and which ones they are not.

Medically Assisted Abortion

As we move through this section we will be speaking about elective abortions for the purpose of preserving the health of the mother or when the baby has a complication not compatible with life. This can be a hard subject to navigate and often comes with many social pressures on the client.

First Trimester

Medical Elective Abortions

- **Methotrexate & Misoprostol (MTX):** A medical abortion procedure used up to the first seven weeks of pregnancy. This procedure is not commonly used in the U.S.

- **Mifepristone and Misoprostol:** Medical abortion procedure used up to the first seven to nine weeks of pregnancy. It can also be referred to as RU-486, the abortion pill, and mifeprex.

- **Multifetal Pregnancy Reduction (MFPR):** A procedure to reduce the total number of fetuses in a multifetal pregnancy by one or more. This procedure involves a potassium chloride injection into the fetus's heart. As a result of the injection, the heart stops and the fetus dies, but this may take up to an hour to occur. Generally the fetal material is reabsorbed into the woman's body.

- **Selective Reduction**: A procedure to reduce the total number of pregnancies by one. This procedure involves a potassium chloride injection into the fetus's heart. As a result of the injection, the heart stops and the fetus dies, but this may take up to an hour to occur. Generally the fetal material is reabsorbed into the woman's body.

- **Methotrexate:** This type of medication is used in the case of a diagnosed ectopic pregnancy at 6 weeks or less. The medication is injected and is considered non-invasive. If the medication fails to terminate the pregnancy a laparoscopic salpingostomy will need to be performed.

Surgical Elective Abortions

- **Manual Vacuum Aspiration (MVA):** A surgical procedure used as early as 3-12 weeks since the last period. Considered less invasive with only local anesthesia being used on the cervix.

- **Dilation and Curettage (D&C):** A surgical abortion procedure used to terminate pregnancy up to 16 weeks from the last period. It can also be referred to as suction curettage, aspiration or vacuum aspiration. This procedure involves the dilation of the cervix by means of induction, followed by the use of an instrument, curettage, to remove the contents of the uterus.

- **Laparoscopic Salpingostomy:** Used to remove an ectopic pregnancy. This procedure involves a surgical incision into the fallopian tube and removal of the developing fetus.

  The procedure is done under general anesthesia. Methotrexate may be given along with the surgery to make sure there is no more cell growth. If the fallopian tube was damaged by the growing fetus beyond repair, removal of the fallopian tube may be necessary.

Second Trimester

Medical Elective Abortions

Medication-based procedures are not an option in the second trimester.

- **Artificial Induction:** A procedure involving an induction without intention of providing resuscitation or any life sustaining measures once the baby is born.
- **Multifetal Pregnancy Reduction (MFPR):** As described above
- **Selective Reduction**: As described above

Surgical Elective Abortions

- **Dilation and Curettage (D&C):** As described above
- **Dilation and Evacuation (D&E):** A surgical abortion procedure used to terminate a pregnancy after 16 weeks gestation. The procedure involves the same methods as a D&C with the added assistants from the care provider to guide the baby out of the cervix and vagina. After 16 weeks varying stages of ossification have taken place making it more difficult for the baby to pass through the vagina without additional assistance. This may include the use of forceps and/or the mechanical collapse of the fetal skull to fit more easily through the cervix and vagina.
- **Induction Abortion:** A surgical procedure where salt water, urea, or potassium chloride is injected into the amniotic sac; prostaglandins are inserted into the vagina, and pitocin is injected intravenously.

Third Trimester

Medical Elective Abortions

Medication-based procedures are not an option in the third trimester.

- **Artificial Induction:** As described above

Surgical Elective Abortions

- **Induction Abortion:** As described above

- **Dilation and Extraction (D&E):** As described above

- **Hysterotomy abortion:** A surgical procedure where an incision is made in the uterus to manually remove the baby from the womb much like a traditional cesarean for a full term live birth with a few exceptions. The hysterotomy is performed under general anesthesia and while the fetus is still in the womb the umbilical cord is cut which cuts off the oxygen supply to the fetus resulting in the death of the baby.

Unexpected Stillbirth or NICU Stay

While the occurrence is rare, families sometimes experience a stillbirth or complication needing a NICU stay at birth. A full-term baby may be in need of NICU care for a number of reasons including:

- Miscalculated gestational age (baby born prior to 37 weeks or after 42 weeks based on a miscalculation of due date)
- Low birth weight (less than 2,500 grams)
- Small for gestational age
- Fetal distress during labor
- Respiratory distress
- Undetected breech presentation at birth
- Abnormal presentation (face, brow)
- Presence of meconium
- Meconium aspiration
- Undiagnosed birth defects
- Compression of the umbilical cord during pushing
- Nuchal cord
- Assisted delivery (forceps, vacuum)
- Cesarean delivery
- Birth related injury
- Resuscitation needed in delivery room
- Presence of certain infection (GBS, herpes, chlamydia)

At some point during labor the infant may experience fetal distress where heart tones decrease or are not able to be detected at all. There will likely be an increase in interventions by staff. If birth is imminent the mother will be directed to push as hard as she can.

Resuscitation efforts will begin as soon as the head is born with bulb suction at the perineum. Vigorous resuscitation attempts may be required. This often occurs with immediate cord clamping and placing the baby in the radiant warmer while resuscitation efforts are used. If birth is not imminent an emergency cesarean section will be performed. Resuscitation efforts will take place after the procedure.

If resuscitation efforts fail the family will be informed and asked if they would like to see or hold their baby. The baby will be swaddled prior to being handed to the family. If abnormalities are present staff will likely attempt to cover them.

If a cesarean section was performed the infant may not be able to be viewed or held until after the parents are back in the recovery room. Parents may be offered to hold their baby skin to skin.

Parents are often given time and privacy to grieve their loss. This may include an onsite photographer, opportunity to bath infant, and dress infant. The placenta may be released to the parents for encapsulation or ceremonial purposes. A lactation consultant will be available for those who want to donate their colostrum.

The baby may need to be transported to the onsite morgue or the hospital may have a cuddle cot available to spend more time with the infant. A cuddle cot is a cooling system that preserves stillborn babies. The infant may be released to the family to take home.

The family will need to choose if they want the infant buried, cremated, or wishes the hospital be in charge of "disposal". If the family has not chosen a mortuary the staff may be able to help provide options or a local funeral home that may offer special pricing for stillbirth. The family may request a representative of the funeral home come to the hospital and to have the baby stay with them until the representative arrives.

Creating a Birth Plan for a Known Loss

A brief birth plan may have been created in the event of an unexpected loss, but a more detailed and personal plan can be made when a loss is known or expected. A first trimester loss may offer a more limited range of options. Second and third trimester losses offer many of the options as a full-term delivery, but there are a few exceptions that may require additional authorization. Families with a fatal diagnosis who do not expect baby to live for long after birth can have a detailed immediate postpartum plan to accommodate an unknown time frame with the child. A farewell celebration may also be planned when creating a birth plan. A sample birth plan is provided at the end of the chapter.

First Trimester Hospital or Doctors Office

The options a family has for a first trimester loss are more limited than losses in later trimesters. If the procedure is taking place at a hospital a woman may be placed under general anesthesia and be released a few hours after the procedure. If the procedure is taking place in a doctor's office a local anesthesia may be used and the woman will be released in less than an hour.

The woman should have a support person with her through the process and have someone available to drive them home. The hospital may have a chaplain on hand for those who wish one to speak with before or after the procedure.

During the procedure pain relief medications are usually offered. Some of the medications offered by hospitals include morphine, valium, Vicodin, naproxen, and ibuprofen. Families may wish to bring headphone to listen to music so they do not have to listen to the sounds of the procedure. Some women wish to have a focus item such as a picture, object to hold, or affirmations during the process.
After the procedure many women are discouraged from or not permitted to view the remains.

If the family wishes to have the remains returned to them a special authorization may be obtained, but many hospitals and offices do not allow this. In the event the family is allowed to take the baby home it will likely have to wait until after testing is done. Families may desire to leave keepsakes with the baby such as a photograph of the family, blanket, or small stuffed toy.

When the family has returned home they should have support at home. A woman will need time to recover and should rest as much as possible in the days after. A family may choose a special farewell celebration or have a goodbye to be spoken in privacy.

First Trimester Home

Many families choose to go through the process of loss naturally and in the privacy of their own home.

The family should prepare some supplies ahead of time including:

- Heavy maxi pads
- Several large towels
- Small fish net (if the desire to retrieve the remains from the toilet)
- Shallow container with saline water to preserve the fetus
- Small container if burial is desired

Any over the counter pain medications that do not conflict with nursing of a current infant would be available to ease discomforts. Labor symptoms may start and stop many times for hours or days between. The woman should never be alone during a loss. She should stay hydrated and nourished. Families will need to decide if they would like to bring the remains to the hospital after the loss, have a burial, or would like to send the remains away down the drain. With each option there are special considerations and rituals that can be performed to make the loss more meaningful.

After the birth the family will need to decide if they will be going to the hospital or staying at home. If the family chooses to go to the hospital they will need to pack a bag. They may want to include keepsakes to be left with the baby or left at the hospital as a symbolic goodbye.

If the family chooses to stay home they will need to have someone with them for the next few days. A woman will need to recover and rest. Particular attention should be place on looking for infection, fever, severe abdominal pain and other signs of serious complications. Lochia will be present, but bleeding should exceed soaking through a maxi pad an hour. Families may wish to plan a farewell celebration.

Second Trimester Hospital

If an operative birth is taking place the options are similar to that of a first trimester hospital birth. If a natural birth or induction birth is taking place there are more options available. The bag to take with the family to the hospital will contain the same suggested items as a full-term birth with the addition of optional keepsake items to leave with the baby.

During the labor the family may wish to create a calmer birthing environment with items like dimed lights, music, candles, essential oils, and birth affirmations. Comfort measures in the form of positions, movement, water therapy, massage, and self-hypnosis may be desired. A family may request the heart rate monitor be turned off or lowered. The use of a heparin lock or telemetry may be requested to retain freedom of movement. Many of the same pain relief medications as a first trimester birth are available along with the options of patient controlled analgesia and an epidural.

During birth the family has many of the same choices as with a full term birth. They may request a mirror, touch the baby's head while crowning, directed assistance on how to push, or have a photographer present.

It may be required to have an assisted delivery with forceps, vacuum or episiotomy. The cord will likely be cut and clamped immediately, but the cord may be cut longer than usual so a partner or family member may trim it at a later time. The birthing mother may request the baby be held by a partner or support member until they are ready to hold the baby.

After the birth of the infant, the birth of the placenta will take place. The family may request the placenta be released to them for encapsulation or ceremonial purposes. The family may choose to hold their baby immediately. Privacy and time are usually given to families to grieve with their baby. Some hospitals have cuddle cots to preserve the infant. Families may choose to bath and dress their baby. Families may request as many mementos as possible this includes items like lock of hair, foot prints and handprints, records of weight and length, baby medical bracelet, baby hat, and keepsake birth certificate. The parents have the right to name their baby, bond with it and have cultural and religious practices observed.

Some hospitals have a special melody that is played after a baby is born. Some families may ask this melody be played or request it not be played. Some families may wish to move from the maternity unit after the birth for the remainder of their stay.

Parents may choose to donate their baby's body or request an autopsy, pathology exam, or genetic testing. Depending on the state a birth and death certificate may be available to families. The family will need to choose if they want the infant buried, cremated, or wishes the hospital be in charge of "disposal". If the family has not chosen a mortuary the staff may be able to help provide options or a local funeral home that may offer special pricing for stillbirth. The family may request a representative of the funeral home come to the hospital and to have the baby stay with them until the representative arrives. In some cases the baby may be release to the family to be taken home.

The postpartum recovery period is similar to that of a full-term birth though it may be shortened. It will need to be decided on if the family would like to donate colostrum or would like assistance suppressing milk production. The woman will need time to recover both physically and mentally after the birth. A farewell celebration may be planned.

Second Trimester Home

A family can choose to have a natural vaginal birth at home in the second trimester. Families should check local and state laws about stillbirth at home, especially if the baby is past 24 weeks and the heart beat has not stopped.

Some laws may determine the birth needs to be at a hospital even if the parents do not wish any life saving measures to be taken. Families should also look into if they would like a medical professional present in case of medical emergencies. Many midwives offer services to support stillbirth at home. It is highly advised to have a medical professional present for this type of home birth.

During the labor the family may wish to create a calmer birthing environment with items like dimed lights, music, candles, essential oils, and birth affirmations. Comfort measures in the form of positions, movement, water therapy, massage, and self-hypnosis may be desired. Pain relief medications will be limited to over the counter medications or alternative therapies.

During birth the family has many of the same choices as with a full term birth. They may request a mirror, touch the baby's head while crowning, directed assistance on how to push, or have a photographer present. The cord will likely be cut and clamped immediately, but the cord may be cut longer than usual so a partner or family member may trim it at a later time. The birthing mother may request the baby be held by a partner or support member until they are ready to hold the baby.

After the birth of the infant, the birth of the placenta will take place. The family may choose to encapsulate or use the placenta for ceremonial purposes. The family may choose to hold their baby immediately. Families may choose to bath and dress their baby. Families may request as many mementos as possible this includes items like lock of hair, foot prints and handprints, or records of weight and length. The parents have the right to name their baby, bond with it and have cultural and religious practices observed. The family needs to decide if they will be staying at home or traveling to the hospital after the birth. Some states require specific authorities be notified after the birth.

They will need to be provided with diagnostic medical documentation to confirm demise prior to labor. The care provider will need to submit information to the local Vital and Statistics office about the baby and may be able to request a birth and death certificate depending on the state.

Parents may choose to donate their baby's body or request an autopsy, pathology exam, or genetic testing. Depending on the state a birth and death certificate may be available to families. The family will need to choose if they want the infant buried or cremated. Families should choose a funeral home ahead of time and request a funeral representative come to their home and release the baby to the representative. In some cases the family may be permitted to bury the infant on their own land.

The postpartum recovery period is similar to that of a full-term birth though it may be shortened. The family will need to decide if they desire to donate colostrum or would like assistance suppressing milk production. The woman will need time to recover both physically and mentally after the birth. A farewell celebration may be planned.

Third Trimester Hospital

If an operative birth is taking place the options are similar to that of a first trimester hospital birth, but the family will likely need to stay overnight. If a natural birth or induction birth is taking place there are more options available. The bag to take with the family to the hospital will contain the same suggested items as a full-term birth with the addition of optional keepsake items to leave with the baby.

During the labor the family may wish to create a calmer birthing environment with items like dimed lights, music, candles, essential oils, and birth affirmations. Comfort measures in the form of positions, movement, water therapy, massage, and self-hypnosis may be desired. A family may request the heart rate monitor be turned off or lowered. The use of a heparin lock or telemetry may be requested to retain freedom of movement. Pitocin may be used in the case of an induction or offered at a point if labor has not progressed in a reasonable amount of time. An induced labor may make labor more difficult to cope with. Pain relief options are the same as a full-term birth.

During birth the family has many of the same choices as with a full term birth. They may request a mirror, touch the baby's head while crowning, directed assistance on how to push, or have a photographer present. It may be required to have an assisted delivery with forceps, vacuum or episiotomy. The cord will likely be cut and clamped immediately, but the cord may be cut longer than usual so a partner or family member may trim it at a later time. The birthing mother may request the baby be held by a partner or support member until they are ready to hold the baby.

After the birth of the infant, the birth of the placenta will take place. The family may request the placenta be released to them for encapsulation or ceremonial purposes. The family may choose to hold their baby immediately. Privacy and time are usually given to families to grieve with their baby. Some hospitals have cuddle cots to preserve the infant. Families may choose to bath and dress their baby. Families may request as many mementos as possible this includes items like lock of hair, foot prints and handprints, records of weight and length, baby medical bracelet, baby hat, and keepsake birth certificate. The parents have the right to name their baby, bond with them, and have cultural and religious practices observed.

Some hospitals have a special melody that is played after a baby is born. Some families may ask this melody be played or request it not be played. Some families may wish to move from the maternity unit after the birth for the remainder of their stay.

In the event of a live birth with a fatal diagnosis the baby may live for minutes, hours, or days. The family will need to decide if they will be giving any life saving measures such a resuscitation or care in the NICU. Families should educate themselves on the diagnosis and what the baby may look like at birth. The family may choose to have the infant stay with them the entire time providing skin to skin care and breastfeeding if possible.

The family is encouraged to bond with their baby as much as possible. Families may request any routine procedures such as shots, eye ointment, or tests be delayed or not performed at all. If the baby lives for longer than expected and is able to be taken home families should be clear on live expectancy and how to care for the infant at home.

If the baby was stillborn or has died shortly after birth parents may choose to donate their baby's body or request an autopsy, pathology exam, or genetic testing. If the baby was born live they will receive a birth and death certificate. If the birth was stillborn, depending on the state a birth and death certificate may be available to families. The family will need to choose if they want the infant buried, cremated, or wishes the hospital be in charge of "disposal". If the family has not chosen a mortuary the staff may be able to help provide options or a local funeral home that may offer special pricing for stillbirth or infant death. The family may request a representative of the funeral home come to the hospital and to have the baby stay with them until the representative arrives. In some cases the baby may be release to the family to be taken home.

The postpartum recovery period is similar to that of a full-term birth. It will need to be decided on if the family would like to donate colostrum or would like assistance suppressing milk production. The woman will need time to recover both physically and mentally after the birth. A farewell celebration may be planned.

Third Trimester Home

Families should check their local and state laws about stillbirth at home especially if the baby's heart beat has not stopped or has a fatal diagnosis.

Some laws may determine the birth needs to be at a hospital even if the parents do not wish any life saving measures to be taken. Families should also look into if they would like a medical professional present in case of medical emergencies. Many midwives offer services to support stillbirth at home. It is highly advised to have a medical professional present for this type of home birth. There is an increased risk of needing medical intervention.

A home environment can be complemented by any of the previously noted birthing environment suggestions and comfort techniques. Birth bonding experiences are available such as guided touching and mirror viewing. The family can have a photographer present.

The cord will likely be cut and clamped immediately, but the cord may be cut longer than usual so a partner or family member may trim it at a later time. The birthing mother may request the baby be held by a partner or support member until they are ready to hold the baby.

After the birth of the infant, the birth of the placenta will take place. Placenta choices include encapsulation, burial, raw consumption, art prints, or jewelry.

Families may choose to hold their baby immediately. Bonding activities may include bathing and dressing baby, naming baby, and talking to the baby. Families may request as many mementos as possible including: lock of hair, foot prints, handprints, and records of weight and length. Parents have the right to name their baby, bond with them, and have cultural and religious practices observed. The family needs to decide if they will be staying at home or traveling to the hospital after the birth.

Some states require specific authorities be notified after the birth. They will need to be provided with diagnostic medical documentation to confirm demise prior to labor. The care provider will need to submit information to the local Vital and Statistics office about the baby and may be able to request a birth and death certificate depending on the state.

In the event of a live birth with a fatal diagnosis laws may require immediate transport to the hospital. The baby may live for minutes, hours, or days. The family will need to decide if they desire any life saving measures such a resuscitation or care in the NICU. These types of care may require a hospital transport. Families should educate themselves on the diagnosis and what the baby may look like at birth. The family may choose to have the infant stay with them the entire time providing skin to skin care and breastfeeding if possible. The family is encouraged to bond with their baby as much as possible. Families may request any routine procedures such as shots, eye ointment, or tests be delayed or not performed at all. If the baby lives for longer than expected the family should how to care for the infant at home. If the baby was born live they will receive a birth and death certificate from any state.

Parents may choose to donate their baby's body or request an autopsy, pathology exam, or genetic testing. The family will need to choose if they want the infant buried or cremated. Families should choose a funeral home ahead of time and request a funeral representative to come to their home and release the baby to the representative. In some cases the family may be permitted to bury the infant on their own land.

The postpartum recovery period is similar to that of a full-term birth. Breastmilk decisions will need to be made by the family. The woman will need time to recover both physically and mentally after the birth. A farewell celebration may be planned.

Preparing the Environment

Front line birth professionals can help create an environment for the bereaved. Hospitals are not typically thought of as warm and comforting places. A caregiver can support a grieving environment by prepping the space ahead of time or upon arrival. Hospital staff can be asked to assist in the process as well.

The environment should convey a space of calm and safety. Parents should feel safe and open to speak about grief and mourning. The space should be accommodating of the family not just the client. An area for baby should be provided. Parents should be able to have a quiet environment. A simple check list may include:

- Does staff know about the circumstances?
- Is unnecessary equipment put away?
- Where is the closest waiting room?
- Can the lights be dimmed?
- Can any needs be anticipated? (water pitcher, tissues)

When Extra Time is Given

When a fetal diagnosis is given, it is unknown precisely how long baby will live after birth or if baby will live through the birthing process. Sometimes baby lives longer than expected after birth. Some considerations should be taken in this circumstance.

Women are encouraged to provide breastmilk. Colostrum can be pumped or hand expressed immediately after birth. Some babies may have difficulty latching or may not be able to latch at all. If this is the circumstance milk can be feed to baby via a feeding tube. If baby is able to latch, baby can be feed every two to three hours. As soon as possible after birth, baby should be encouraged to be at the breast even if a latch is not possible.

Parents are encouraged to hold their baby, talk to their baby, and dress their baby. Immediate skin to skin contact after birth is recommended, but keeping in mind how baby might respond to stimulus. Babies born early have undeveloped nervous systems and do not tolerate touch well. Rubbing or stroking can be painful or upsetting for the baby. Pay attention to baby's cues such as a dropping heart rate or lower oxygen saturation as these can be a sign baby needs less stimulation. Meaning making, prayer, and photographer are also good options for parents with an unknown amount of time with their baby.

If the baby remains in the hospital NICU parents can bring personal items for the baby's room. This can include stuffed animals, pictures, or blankets. Some families cannot stay at the hospital for extended periods of time due to finances, lack of space, or older sibling care. Families can leave items with baby that smell like the members of the household. Items like burb cloths and receiving blankets work best, so the child can sleep with them. Breastmilk can be dripped on a cloth and left with the baby.

Some babies will be able to go home with the family for an unknown length of time. Parents will need a carseat for transportation. Parents can make nursing decorating a special experience. Take time one day at a time and celebrate all the moments with the baby. Document baby's firsts such as baby's first bath, meeting relatives for the first time or the first time baby can feed out of a bottle.

Sample Birth Plan For a Known Loss or Fatal Diagnosis

The following is an example of a birth plan for when the baby is known to be a stillbirth or has a fatal diagnosis.

What to Pack

- Personal labor gown (if desired)
- Cell phone chargers
- Camera
- Music
- Birth ball
- Lotion or massage oil
- Electric candles
- Snacks
- Pillows
- Warm Socks
- Personal care products for mom and partner
- Special items for baby (two teddy bears or blankets, one to leave with baby the other to take home)
- Baby outfit
- Going home outfit for mom
- Night gown or robe

Labor Options

Environment choices

- Dimmed lights
- Soft music
- Birth affirmations

Medical Options

- Heart rate monitor turned off or silenced
- Heprin Lock vs IV
- Use of Pitocin
- Epidural

Comfort measures

- Massage
- Hydrotherapy (shower head, bath, birthing tub)
- Hot/cold therapy with washcloths
- Intimacy with partner

Crowning/Delivery Options

- I would like to us a mirror to see baby's head crowning
- I would like to be directed to touch baby's head while crowning
- Assisted delivery is okay if necessary (forceps, vacuum)
- An episiotomy is okay if necessary
- Umbilical cord cut by partner unless medical emergency
- I would like photography

After the Birth

- Have baby be swaddled in a blanket and placed with mother
- I desire to forfeit all standard medical support and focus on bonding
- I would like baby weighed and measured at least an hour after birth
- I would like life saving medical support
- I would like pain medication administered if my baby is in pain
- I would like baby to remain with me as long as possible
- I would like to give baby a bath
- I would like my postpartum room away from the maternity floor
- I would like a lock of baby's hair if possible
- I would like to utilize meaning making, including saving mementos, holding baby, capturing baby's smell with a blanket to take home, dress baby, name baby, taking photographs.

Chapter

Bereavement in Practice

"We bereaved are not alone. We belong to the largest company in all the world – the company of those who have known suffering."
—Helen Keller

The Unknown

It is often unpredictable when bereavement services will be needed a birth professional should have a personal set of protocols they set into motion when needed. You should make note of all the ways you may be able to support a family in their time of loss. The plan should take into account when the loss may take place. Find ways to honor and witness the family's grief. Your ultimate goal is to offer the family the most positive experience possible.

Communication

Communication is crucial to most events in our daily lives. In bereavement it is especially important and can be used as a tool to facilitate the process. Practice compassionate conversations with active listening throughout your time with the family.

Parts of compassionate conversations with active listening include:

- Enter the space and wait till the family is ready to listen
- A short introduction: Hello I am Angie, your nurse for the next shift
- An expression of empathy
- Be aware of your body language
- Be comfortable showing emotions
- Choose your words carefully
- Give yourself ample time
- Remove any distractions: phones, tv, outside hallway noise
- Listen to their story
- Ask questions to confirm your understanding
- Allow for silence
- Answer questions honestly
- Share stories of others when appropriate
- DO NOT : use medical jargon, argue with parents, avoid questions

Communication is part of informed consent and informed decision making. Families need information to make choices. Make sure to present information in the clearest way possible. Offer all possibilities one at a time and allow time to revisit the conversation. Avoid the use of medicalized language and make sure families are familiar with terms used. This may include the use of miscarriage instead of spontaneous abortion or fragile skin instead of maceration.

What to Say

"I am sorry"
"I wish things would have ended differently"
"I don't know what to say"
"I feel sad," or "I am sad for you"
"Do you have any questions?"
"We can talk again later"

What Not to Say

"It's the best way"
"It could be worse"
"You can have more children"
"Time will heal"
"It's good your baby died before you got to know them"

Arrival at the Hospital

When parents arrive at the hospital for a suspected problem or a known loss the process can be overwhelming. Families often need a constant point of contact to support them and guide them. Make contact with clients prior to arriving at the hospital. Know where you will meet them and make sure the family knows where they are going. Be prepared with a plan. Support a smooth transfer to room and caregiver. Admission procedures can be confusing and frustrating.

Once admission has taken place be prepared to support the family for the length needed. Bereavement care may last hours or even days. Approach the situation as a team effort. Offer physical, emotional, and informational support during the process. Actions to be taken after the death of a baby:

- Assure parents that it is normal to feel uncomfortable at this time
- Allow parents to spend as much time as they need with their baby
- Encourage families to bond and hold baby
- Make repeated offers for holding the baby
- Treat the baby with the same care as you would a live child (swaddle baby, carry baby in arms, refer to baby by name)
- Name the baby
- Provide privacy, but do not abandon the parents

- Encourage relatives and friends to see the baby, according to the parents' wishes
- Warn about gasping and muscle contractions
- Reassure parents that their baby was not alone, not afraid and not in pain at the time of death
- Reassure parents that nothing more could be done
- Provide mementos to create memories
- Ensure that spiritual support is available
- Take pictures
- Explain the need and procedure for an autopsy
- Explain options and procedures for memorial services

Bonding with Baby

Some families wish to remove themselves from everything to do with the loss as soon as possible. Other families wish to make the loss special and celebrate the life that was and create memories to be cherished for years to come. The following are ways to encourage parents to bond with baby.

Holding Baby

Parents can benefit from spending a prolonged period of time with their baby after death. Parents are encouraged to talk to their baby. Parents are able to express their love in tangible ways such as examining the body, admiring them, and snuggling them. Parents may introduce baby to other siblings or other family members.

Special outfit for mother and or baby: Some companies such as Dressed to Deliver, Pretty Pushers, Push, or Etsy have designer hospital labor and delivery gowns. These gowns offer modest coverage, access for hospital monitors, and allow women to feel more comfortable in something they picked out. It can be nice for photography. There are also matching mother and baby outfits a family may wish to use.

Families may also wish to have a special outfit for the baby only. Picking out the outfit may be made into a special family bonding time while they anticipate and prepare the loss of their baby. A pre-made outfit may be selected or they may choose to have one made for their baby special. An outfit the opens completely from the front or back is suggested to limit the amount of rubbing of the skin when placing baby in the outfit. Some suggestions for clothing selection:

- Baby should be dressed in a typical outfit not a burial gown
- Clothing should be appropriately sized
- Use soft fabrics such as flannel, fleece or knit
- Include a diaper

Bathing and Dressing Baby: Parents may wish to bath and dress their baby after birth. Families should understand they are qualified for providing after-death care and it is completely legal for them to do so. The process of bathing and dressing a stillborn is a delicate process.

Depending on how long the death in utero took place will affect the appearance of the infant's skin. Some of the skin may already be peeling away and washing may encourage more skin to come off. A wash cloth should not be used on the skin. A wash cloth may be used to absorb water and sprinkled over the infant's body. A small basin filled with warm water and baby shampoo may be used. When drying the baby a towel or chux pad may be used, but should be dabbed not rubbed. Gauze wraps may need to be placed over areas of damaged skin or transparent dressing may be used over weeping areas.

A diaper may be placed on the infant before being placed in an outfit. If seeping from the nostrils occurs a small amount of Vaseline may be placed under each nostril to prevent further leaking. After the bath an absorbent towel is recommended to be placed between the baby and blanket to absorb and further seeping.

Breast milk considerations

Losses in the first and early second trimester are less likely to involve the production of colostrum and breastmilk. Second and third trimester miscarriage, still birth, or neonatal death will typically result in the production of colostrum and mature milk 2-7 days after the birth. Families will need to decide if they will be doing any level of donation or would like to support in suppressing their milk production.

Some consideration and education should be given to clients about the risks and benefits of pumping, hand expression and donation options. Recent studies have shown that early involution (stopping lactation) increases a mother's risk of postpartum depression and breast cancer. The benefits to the mother include release of oxytocin to stimulate contractions in the uterus, reducing risk of postpartum hemorrhage and promoting the uterus to return to pre-pregnancy size, aids in hormone regulation after birth, and aids in weight loss.

Some women seek to end lactation as soon as possible so they may move away from the loss more quickly. This option should be respected, but families should be able to make it based on an informed decision. Families should seek assistance from a lactation consultant or breastfeeding counselor for any option they choose.

Pumping, Hand Expression, and Donation

For both mental and physical benefit, it is recommended mothers pump or hand express for a short time after the birth of a baby. Pumping may help the mother validate that she is in fact a mother and help in the grieving process. It is not encouraged to pump for a prolonged period of time as this may cause unnecessary emotional distress for a family that has experienced a loss. Pumps may be rented from the hospital or small hand pumps may be purchased at a grocery store for as little as $20.

Donating expressed or pumped breastmilk may allow another level to the healing process of grief. Mothers find a positive meaning about donating knowing they are helping other babies in need with the donation of their breastmilk. There are many donation programs across the U.S. which include milk bank donation or mother-to-mother sharing. Milk bank donations have restrictions and limitations such as minimum donation amounts, blood tests, and certain medications that may make the milk not fit for donation such as some over the counter herbs or pain medications. Some of the mother-to-mother sharing programs include Eats on Feet, MilkShare, and Human Milk 4 Human Babies.

Breastmilk Suppression

If pumping or expression will not be done it can take 1-2 weeks for a mother's milk supply to dry up. This can be an incredible delicate time for the mother both mentally and physically. Initial engorgement may be extremely painful. The following are tip to help ease discomfort and encourage milk suppression:

- Avoid heat as it can stimulate milk letdown and increase milk production
- Use cabbage leaves placed in the bra
- Wear a supportive but not tight bra
- Do not bind the breasts
- Stay adequately hydrated
- Avoid breast stimulation
- Use ibuprofen for pain
- Use cold packs or soothing gel inserts to ease pain
- Decrease salt intake
- Use milk inhibiting herbs such as sage
- Hand express to comfort if engorgement becomes too much but try to only do it as little as possible

Chapter 7

Meaning Making

"Grief is in two parts. The first is loss. The second is the remaking of life."
– **Anne Roiphe**

Bringing Meaning During Bereavement

Part of the care offered in bereavement is assisting in meaning making with the parents. This may also be referred to as memory making. We want families to have memories of the experience other than pain. A distinction should be made about caregivers and the making of memories; we can aid in making a moment special, but we do not create memories.

As a family goes through the bereavement process there are some key moments we can assist in imprinting. Our memories are recorded with our senses. We can enhance some of their memories by encouraging sensual memories. Families have physical memories such as holding the baby, seeing the baby, and smelling them. Most of our memories are intangible.

Intangible memories are formed and interpreted by the individual. This means two people in the same experience can remember it differently. Some of the ways to enhance these moments include:

- Wrapping baby in a warm blanket after delivery
- Ensuring the lighting in the room is soft and warm
- Dress baby in colors and subtle textures
- Keep baby dry (sometimes the baby's skin may weep and need an absorbent gauze to be wrapped before dressing)

Remembrance Photography

Some families at first do not think pictures of their baby will be something they want, but many families are thankful they took pictures. Now I Lay Me Down to Sleep, is a company dedicated to providing volunteer photographers who specialize in photographing stillbirths and babies who are no longer living. They also offer picture retouching for other photographers who would like images they took to be professionally edited.

It is not encouraged for the doula to offer photography if they do not have photography training. This event will only happen once and it can cause undue stress if pictures are taken that cannot be given to the family. You are encouraged to take photos if the family requests, but you should not advertise or offer professional photography without proper equipment and knowledge. Having a photographer in the room can be an additional hardship for the family, especially one who is not mindful of camera sounds, voice level, flash, or time spent in the room.

If a doula or other birth professional is taking photos here are a list of shots to make sure to get:

- Hospital entrance
- Room number
- Moms ID bracelet
- Baby's ID bracelets
- Parents bonding with baby
- Close ups of baby (face, hands, feet)
- Baby's hand touching parent's hand
- Baby in size relation to parent's hand or teddy bear

Mementos

There are many mementos that can be created after the birth of the baby. Not all of them may be possible.

Ink Prints: The most common item done at a birth include ink prints of the feet and/or hands of the baby. Most hospitals will assist in this process, but DIY kits are also available. The hospital may have keepsake birth certificates or you may want to bring one yourself.

Lock of hair: Depending on gestation and specific baby this may not be an option. If a lock of hair is removed a small ribbon or band should be used to secure it together and it should be placed in a dry storage container. This may be a small plastic ziplock bag.

Hand and Foot Molds: There are a few different types of molds; press molds or 3D molds. The press molds involve pressing the baby's hand and/or foot into a malleable solution that quickly dries leaving the imprint of the hand and/or foot. Kits can be purchased or hand made. A 3D mold is a bit more complex and involves mixing a quick drying solution, placing the hand/foot submersed into the solution until it dries, removing the hand/foot, allowing the mold to completely dry, then filling the mold with plaster.

Accepted Refusal

Sometimes a family may refuse to see, hold, or touch their baby. They may not be interested in making the event special in any way refusing any mementos or photography. The family may be upset or angry at their situation. It is okay for the family to react this way. As their doula you should respect their wishes. At the same time it may be hard for a family to realize this is their only chance to make any memories or bond with their baby. You can gently offer them the option to see their baby again at a later time in the hospital stay.

Placenta Options

Parents have options when it comes to what they can do with their placenta. Some families may wish to not do anything with their placenta and may ask the hospital to dispose of the placenta. Placenta option may not be available for those who experience a loss in the first or early second trimester due to the condition the placenta may be in. Options include encapsulation, burial, or using the placenta to make memorial jewelry or art prints.

Encapsulation: This option may help with hormonal transition and help with postpartum depression. A medical provider should be consulted as to the condition of the placenta in the case of a stillborn. Changes to the placenta begin to take place soon after the infant no longer has a heartbeat which may make the placenta not safe for consumption. Factors affecting the placenta include time from infant death, bacteria, temperature, and potential maternal infections. Most encapsulationist also provide a dried umbilical cord keepsake as well.

Placenta Art Prints: Placenta prints involve taking the placenta, applying ink or paint to the placenta, and pressing the placenta onto a sheet of paper. The prints will need to be done with a fresh placenta that has been refrigerated or frozen shortly after birth. A placenta encapsulationist may provide this service free of charge in the event of a stillborn or a neonatal death.

Placenta Jewelry: A growing number of providers and companies offer personalized jewelry made with pieces of placenta, breastmilk, and/or umbilical cord pieces. The process usually involves taking the piece, freeze drying it, and placing it under clear resin. Breastmilk jewelry usually involved an epoxy resin to dry the milk and it is then shaped into a bead or gem to be used in a pendant, necklace, bracelet, earing or ring.

Chapter

Planning for After

"No one ever told me that grief felt so like fear."
— C.S.Lewis

Funeral, Cremation or Memorial Service

Most parents do not walk into a hospital with a plan for a funeral. If possible both parents should be involved in planning and participating in a funeral or memorial. Other family members may try to unburden the parents of the task of planning these types of event, but may cause harm to the grieving process. One of the first steps is to select the funeral home. Parents should make sure they are comfortable with the attitude of the funeral director and feel they will be sensitive to their needs as newly bereaved parents. Parents should consider their options and keep in mind location, flexibility of service options, coordination options, and payment arrangements. If it is too difficult for parents to speak with the funeral home directly they may work closely with a family member or hospital staff to communicate and coordinate the family's requests.

There are two types of funerals. One with is with the infants body present with or without viewing. The other type of funeral involves the cremation of the body. Parents may choose to keep the ashes in an urn at home, bury the ashes, or scattered the ashes at a desired location. Some parents choose to make a special token or piece of jewelry that contain the ashes.

A memorial is similar to a funeral except that the body or ashes are not present. A memorial may still take place at a funeral home or may take place in a desired location more significant to the family. Ideas for the ceremony include:

- Choosing a special song to eulogize the infant. Parents should listen to the words several times and make sure they have meaning to them. They may want to print the words to the song on special paper and hand them out to friends and family at the memorial service.
- Bring a special stuffed animal such as a lamb, toys from siblings, cards and letters from siblings, a special necklace for the infant to be buried with.
- Parents may choose a special outfit and a special blanket for the infant to have on in the casket.
- If a spiritual leader or pastor speaks at the memorial service, it is a good idea to limit the sermon to 15 minutes maximum.
- Parents are encouraged to write a letter to the infant. The letter should be read by a close friend or family member on behalf of the parents. The letter should be about the feelings of grief, loss and love for the infant.
- A special poem or two may be used as a eulogy.

- Open casket services help to make an infant more "real" to others.
- Parents may ask others to send stuffed animals or toys instead of flowers. After the services, parents can choose to donate to a local charity on behalf of their child
- Parents may make a tape of their own favorite songs so they are not limited to the choice of the funeral home.
- The parents should strongly consider closing the casket for the final time.
- The family can request to shovel the first dirt. This is a therapeutic ritual for many. Guests may also take a handful of dirt and sprinkle it onto the grave. Parents may stay with their child until the cemetery staff has completely buried their child.
- If possible, a ceremony at sundown is beautiful. Consider a graveside unity candlelight service. This is a service where one larger candle is lit, and each person lights their candle off the main unity candle in honor of the child.

Other Options to Honor/Memorialize an Infant After Loss

Farewell Ceremony: Sometimes a funeral is not an option for a family, but they would still like to hold a special ceremony to honor their baby. The family may choose to have a farewell ceremony. This can include any number of things the family wishes to do to honor or memorialize their child. It can be a private event with only the parents and siblings or it may include other family members or close friends.

The ceremony may include reading from a spiritual book, a poem or letter the parents wrote for the child, or words of goodbye. The event may include an unofficial burial (explained below) or if applicable an actual burial of remains on private property. Some families may choose to have a symbolic release of their child with a balloon release, sky lantern release, or the release of an item into a river or ocean.

Unofficial burial: In circumstances where families are not able to bury any remains they may choose to have an unofficial burial. This consists of burying other items that symbolize the infant like a baby outfit, ultrasound pictures, blanket or small toy. It may involve a funeral like ceremony or may be a private experience for just the parents.

Remembrance Crafts: As a process of grief or as a means of memorial some women make crafts. Some will make them for private use and viewing only while others may choose to make many and donate or sell them. This may include:

- Paintings
- Shadow Boxes
- Memory Book
- Memorial Candle Holder
- Pillow
- Christmas Ornament
- Needle Work
- Rock Art
- Quilts
- Crocheted items like blankets, outfits, or hats

A Tangible Item: Some families wish to have a physical reminder of their loved one after a loss. This may include a special piece of jewelry, art work, book, wind chime or tattoo. There are many organizations that offer specific keepsake items for families who have experienced a loss. Another option is to repurpose clothing and blankets to make into a quit or teddy bear.

Create a Memory Box: This option can contain objects from the birth as well as items from pregnancy. This may include:

- Pregnancy test results
- Appointment cards from the doctor's office
- Sonogram pictures
- Memory book
- Footprints and/or handprints
- Stuffed animals
- Hospital bracelets

- Photos of mother pregnant, even if they don't yet look pregnant
- Flowers and cards expressing sympathy after your baby died
- Anything used while caring for your baby
- Hospital birth certificate or Stillbirth certificate
- Baby blanket and/or other articles of clothing
- Letter written by parents to child
- Cards and/or flowers of congratulations when you announced your pregnancy

Tree, Flower, or Memorial Garden: Planting of a tree, flower, or garden could be set aside as a memorial for a loss. The family may choose the forget-me-not plant as a special symbolization.

Charity Fundraiser or Donation: The family may choose to do this once or as a reoccurring event. They may choose to donate the money to the hospital to help other families who are experiencing loss or to a specific charity relating to a fatal diagnosis or disease. A one time or reoccurring donation can be made to a charity of the family's choice in the infant's name.

Adopt a Cause Special to the Family: This option includes a variety of choices. A family may choose to adopt a section of highway or trail in honor of their baby. The family may choose to walk in the March of Dimes' Walk America or take up running a specific marathon in honor of their baby each year. Families can name a star after their baby. Some families choose to help others in similar experiences with public blogs, getting involved with the hospital bereavement program or starting one if the hospital does not have one, or starting their own non-profit to help others.

Birth Certificate & Death Certificate

The laws on birth and death certificates vary from state to state. Become familiar with the laws in your state. Some states issue a certificate of birth or a certificate of stillbirth. If a legal birth certificate is not available in your state check to see if the local hospitals in your area provide keepsake birth certificates for families and if they are available for families who give birth in any trimester. If none of the previous certificates are available for your clients you may choose to make a certificate yourself or use the BABES certificate of birth template. You may provide your clients this certificate at the postpartum visit along with any other mementos you helped gather/create for the family.

The following 34 states have laws in place to provide a certificate stating Certificate of Birth:

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Florida
- Georgia
- Indiana
- Iowa
- Louisiana
- Nebraska
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Maine
- Maryland
- Massachusetts
- Minnesota
- Mississippi
- Missouri
- Montana
- Oklahoma
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Virginia
- Wisconsin

Some states have fetal death certificates available for parents. The official definition of fetal death states:

"Fetal death" means death prior to the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy and which is not an induced termination of pregnancy.

The death is indicated by the fact that after such expulsion or extraction, the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles. Heartbeats are to be distinguished from transient cardiac contractions; respirations are to be distinguished from fleeting respiratory efforts or gasps."

The specific fetal death reporting requirements by registration area are listed as follows:

All products of human conception:

- Arkansas
- Colorado
- Georgia
- Hawaii
- New York
- Rhode Island
- Virginia

20 weeks of gestation or more:

- Alabama
- Alaska
- California
- Connecticut
- Florida
- Illinois
- Indiana
- Iowa
- Maine
- Maryland
- Minnesota
- Nebraska
- Nevada
- New Jersey
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Texas
- Utah
- Vermont
- Washington
- West Virginia
- Wyoming

Birthweight of 350 grams or more or 20 weeks of gestation or more:

- Arizona
- Delaware
- Idaho
- Kentucky
- Louisiana
- Massachusetts
- Mississippi
- Missouri
- Montana
- New Hampshire
- South Carolina
- Wisconsin

Gestation of 20 weeks or more or birthweight of 400 grams or more:

- Michigan

Gestation of 20 weeks or more or birthweight of 500 grams or more:

- District of Columbia

Birthweight of 350 grams or more:

- Kansas

Birthweight of 500 grams or more:

- New Mexico
- South Dakota
- Tennessee

Gestation of 16 weeks or more:

- Pennsylvania

Each state has different particulars in how to file for a fetal death certificate. All require collaboration with a medical professional to provide documentation of pregnancy and verification of the circumstances regarding the loss. The death must be reported within 5 days to the proper authorities.

Testing for why

Some hospitals require a pathology report of the placenta to determine cause of death. Parents can decline this test or may request the results not be told to them. Parents may be asked by medical care providers if they wish to have additional testing done to attempt to determine cause of death. Parents may decline. Parents may also request additional testing be done. Some testing may including possible out of pocket costs for parents. Some of the tests that may be performed may need to be done prior to the birth after a loss has been detected such as an amniocentesis. Genetic tests may be performed on client and/or the baby to check for genetic abnormalities. Tests may also be done to check for maternal infections, infections on the baby, or infections in the placenta. A detailed family heath history may be done to look for family problems or illnesses that could have caused the loss.

The information from the tests could be helpful to parents or it could add an additional layer of difficulty if the tests come up inconclusive or they are not able to find any abnormalities. The information could help parents determine if they wish to get pregnant again or predict increase chances of future miscarriage or stillbirth.

Coroner Reports

Parents may wish to have an autopsy done to determine cause of death. This report may be used to obtain a death certificate. An autopsy is a physical examination of the infant's body after death. During an autopsy, a provider checks the baby's organs for signs of birth defects or other problems. The findings may help determine cause of death and whether families may be at risk of having another stillbirth in the future. An autopsy may conclude an unknown case of death.

Chapter 9

Postpartum Care

"We do not "get over" a death. We learn to carry the grief and integrate the loss in our lives. In our hearts, we carry those who have died. We grieve and we love. We remember."
— Nathalie Himmelrich

Educating for Postpartum after Loss

Postpartum care instructions from birth professionals are often filled more with newborn care and breastfeeding than care of mother. Education about postpartum after a loss can be difficult for both educator and family. Information given near the time of loss may be fuzzy or forgotten entirely. Birth professionals should rely on multiple avenues of education such as verbal, handouts, and even follow up face to face or digitally. Written instructions should be a must in your protocols. If your hospital does not have a handout consider making your own.

Postpartum education information that should be included:

- Postpartum bleeding – what is normal and when to call a provider
- Signs and symptoms of infection or other problems
- Breastmilk considerations
- First bowel movements
- Exercise – Avoid heavy lifting for 6 weeks
- Excess perspiration
- Perineal Care
- Recovery Rest
- Medications
- Hormone effects – dropping levels, baby blues
- Birth control
- Resources

Healing after loss in the late second and third trimester is often the same as with a live child. Uterine cramps will happen to return the uterus back to its pre-pregnancy size. Cramps worse with each subsequent birth so if a client has had other children their cramps may require medication to alleviate the pain. They subside within the first week after birth. Heavy period like bleeding is normal for the first two days. Then bleeding should taper off from red, to brown, and then white.

Grief Care

We talked about the physical and mental impacts of grief. We should be talking about them to our clients as well. Encourage the entire family to participate in grief care. Verbal and written instructions should be provided to parents about care after loss. If one is not available from the hospital consider making one yourself. It should include things to improve physical grief symptoms such as:

- Self-care: Nutrition, hydration, stress reduction
- Vitamins
- Avoid alcohol
- Exercise
- Rest
- Ask for help
- Support groups
- Resources
- When to call a provider

If a loss occurred late in the second or third trimester a woman's body will still look pregnant. Sometimes women will try to lose the weight quickly by means of exercise and limiting calories. It is important to remind postpartum women about recovery in the first six weeks. A negative body image can add to the feelings of grief. A partner may distance themselves physically and or intimately because the postpartum body is reminiscent of the pregnant body.

Some events can trigger increased grief symptoms requiring additional support. This can include a woman's first menstruation after loss, baby's due date and anniversary of baby's death. Families should be encouraged to seek support during these times.

Emotional Experiences

In the postpartum time the bereaved often experience a myriad of emotional responses. They include the previous grief reactions we have previously discussed as well as others. The following may be experienced following a loss, with an unexpected outcome, or with a baby in the NICU. Birth professionals can keep a look out for symptoms of these feelings or activities in postpartum visits. Clients should be encouraged to look for signs themselves and seek medical attention or support when necessary.

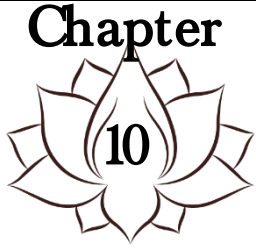
- PTSD
- Sexual change (hyper arousal, impotence, decreased sex drive)
- Disassociation
- Feeling invalidated
- Derealization
- Doubting sanity
- Fleeting feelings of harm

After Loss Care

The outside world is often lacking in understanding for the bereaved family. Friends and family may desire to assist the bereaved in some way, but are unsure how. Support during the postpartum period after loss is important. If a loss is known ahead of time family can prepare, though if the loss is sudden a plan may not have been formulated.

Birth professionals attending the family during this period may be able to support the family beyond education. Some families may be coming back home after a loss and others may be staying close to the hospital with a baby in the NICU. Birth professionals can assist the families support team with the following:

- Meal prep or meal delivery services
- Childcare for older siblings
- Household care (feeding pets, checking mail, snow removal)
- Self-care time (massage, pedicure)
- Alternative living space (hotel, hospital room)
- Spiritual care (prayer, church)
- Planning an outing



Preterm Labor

"You never know how strong you are, until being strong is your only choice."
— **Bob Marley**

When Labor Comes Early

Preterm or premature labor is the term used for any labor that begins prior to 37 weeks. In 2016, the preterm birth rate in the United Sates was 9.6%. Preterm birth rates are a problem in the United States where it lags behind the majority of industrialized countries and some less developed ones in preventing preterm births. A vast disparity between race and preterm birth exist in the United States with black women experiencing a 48% higher preterm birth rate than other races. The state you live in also play a factor in preterm birth rates with the south western states having the highest level of preterm births. Preterm birth is a leading cause of neonatal death in the United States and is the leading cause of neurological disorders such as cerebral palsy.

There are different levels of prematurity.

- Overall preterm: Less than 37 weeks
- Late preterm infants: Infants born between 34 and 37 weeks of gestation
- Moderately preterm: 32-36 weeks
- Very preterm: 28-32 weeks
- Extremely preterm: Less than 28 weeks

The weight of a preterm infant can put it into other sub-categories of prematurity. The weight of a premature infant may not correspond with the gestation of the infant. A 28 week infant may weigh more than a different infant born at 32 weeks. The following are sub-categories based on weight.

- Low birth weight (LBW): Infants weighing less than 2500 grams
- Very low birth weight (VLBW): Infants weighing 1500- 2500 grams
- Extremely low birth weight (ELBW): Infants, less than 1000 grams
- Micro preemies: Infant weighing less than 750 grams or born before 26 weeks gestation

Significance of Preterm Birth

During the typical 42 weeks of pregnancy the fetus goes through stages of development critical to their survival and ability to thrive. When an infant is born prematurely some of their development has not taken place or has not finished. This means they do not have the ability to survive and thrive outside of the womb without help. The earlier an infant is born the higher the risk of immediate health, long-term health, or developmental problems. Those at highest risk are those in the extremely preterm category.

Causes of Preterm Birth

The cause of preterm birth are not always known or may be unclear. There are many factors that place a woman at a higher risk for premature birth and some factors and causes may overlap or contribute to one another. For example; infection is linked to preterm premature rupture of membranes or a woman could have cesarean due to an emergency event like placental abruption. Some women may not have any risk factors present and go on to have a premature birth.

- Labor induction or cesarean for maternal or fetal indications (30-35%)
- Spontaneous preterm labor with intact membranes (40-45%)
- Preterm premature rupture of membranes (PPROM) (25-30%)

Risk Factors for premature birth

- Women with previous premature birth
- Women with twins, or higher multiples
- Women with certain uterine or cervical abnormalities
- Women with late or no prenatal care
- Women with poor nutrition before or during pregnancy
- Women with behavior risk factors, smoking, drinking alcohol, using drugs
- Domestic violence, and lack of social support
- Long working hours and high levels of stress
- Certain medical conditions during pregnancy
    - Infections
    - High blood pressure
    - Diabetes
    - Obesity
    - Being underweight before pregnancy
    - Location of placenta
- Short time between pregnancies (less than 18 months)
- Birth defects in the baby
- Certain demographic factors
- Non-Hispanic black race
- Younger than age 17 or older then age 35
- Poverty or low socioeconomic status
- Fertility treatments resulting in twins or higher multiples

Medical Complications in Premature Infants

Depending on what gestation a premature infant is born will effect what medical complications they are more and risk for and what type of care they will receive. As soon as a baby is born they have several body system changes that need to take place. Some of the major changes that take place include:

- The lungs must fill with air and provide the cells with oxygen.
- The circulatory system must change so blood and nutrients can be distributed.
- The digestive system must begin processing food and excreting waste.
- The liver and immune system must start working independently.

Many premature babies have a hard time making these adjustments on their own. The more premature they are the more likely they will need increase assistance with these changes. The following is a general overview of what type of care a premature infant is likely to have based on their gestation. There are other factors they may come into consideration such as birth weight that may cause a premature infant to need different type of care than noted below.

Extremely Premature (Less than 28 weeks):
At this level of prematurity this baby will be immediately transferred to the NICU. If a NICU or required level of NICU is not available at the hospital the infant will be transported. This may require an ambulance ride, helicopter or life flight.

They will be at the highest risk of health problems and breathing. They will not be able to breath on their own and will require breathing support. They will need to be kept warm to avoid hypothermia and will need to be given dextrose and IV nutrition to prevent hypoglycemia and encourage growth. They will begin to transition to milk feed slowly over the first few days of life by tube feeding. Supplementation with bottles will be available until the infant is strong enough to feed from the breast. They will be at high risk for low blood pressure and infection. There is a high risk of brain injury so they will be closely monitored with ultrasound scans. An incubator will be used to regulate body temperature and bilirubin treatments to treat jaundice.

Very Preterm (28-32 weeks):
At this level of prematurity this baby will be assessed for immediate transfer to a NICU, but may not need as high of a level of NICU as younger infants. If a NICU or required level of NICU is not available at the hospital the infant will be transported. This may require an ambulance ride, helicopter or life flight.

They will be susceptible to many of the health problems as more premature infants but the risk is lower. They will typically need support breathing and are at risk of hypothermia, low blood sugar and infection. These babies are not as likely to become severely ill. Feeding may take place with a feeding tube, but may also be able to attempt feeding from the breast or bottle. An incubator will most likely be used to regulate body temperature and bilirubin treatments to treat jaundice. Babies born at this age have a high survival rate.

Moderately Preterm (32-36):
At this level of prematurity the infant is less likely to have severe breathing problems, but is still at risk of problems with blood sugar levels, blood pressure and infection, and may not be able to breast or bottle-feed immediately . Feeding may take place with a feeding tube, but may also be able to attempt feeding from the breast or bottle. They may still require time in the incubator to regulate temperature.

The following are common medical complications of premature birth:

Respiratory distress syndrome (RDS): A breathing disorder related to the baby's immature lungs. It occurs because the lungs of preterm babies often lack surfactant, a liquid substance that allows the lungs to remain expanded.

Treatment includes Artificial surfactants can be used to treat these babies, along with a ventilator to help them breathe better and maintain adequate oxygen levels in their blood. Sometimes, extremely preterm babies may need long term oxygen treatment and occasionally may go home on supportive oxygen therapy.

Chronic lung disease/Bronchopulmonary Dysplasia (BPD): A term used to describe babies who require oxygen for several weeks or months. They tend to outgrow this uncommon condition, which varies in severity, as their lungs grow and mature.

Apnea and Bradycardia: Apnea is a temporary pause (more than fifteen seconds) in breathing that is common in preterm infants. It often is associated with a decline in the heart rate, called bradycardia. A drop in oxygen saturation as measured by a machine called pulse oximetry is called desaturation. Most infants outgrow the condition by the time they leave the hospital for home.

Retinopathy of prematurity (ROP): ROP is an eye disease in which the retina is not fully developed. Most cases resolve without treatment, although serious cases may need treatment, including laser surgery in the most severe instances. Infants may be examined by a pediatric ophthalmologist or retina specialist to diagnose and, if needed, recommend treatment for this condition.

Neonatal hypoglycemia: A term used to define a blood sugar level of less than 30mg/dL in the first 24 hours of life and less than 45mg/dL thereafter. Treatment involves early feeding with breastmilk or formula. If oral feeding is not possible nasogastric, intramuscular, intraosseous, or intravenous (IV) routes can be used along with the use of dextrose. In rare and severe cases surgery may be needed.

Clinical sepsis/infection: Neonatal sepsis may be categorized as early-onset or late-onset. Of newborns with early-onset sepsis, 85% present within 24 hours, 5% present at 24-48 hours, and a smaller percentage present within 48-72 hours. Onset is most rapid in premature neonates. If sepsis is suspected treatment should be started immediately. Treatment typically includes use of antibiotics.

Early-onset sepsis is associated with acquisition of microorganisms from the mother. Transplacental infection or an ascending infection from the cervix may be caused by organisms that colonize the mother's genitourinary (GU) tract; the neonate acquires the microorganisms as it passes through the colonized birth canal at delivery.
The microorganisms most commonly associated with early-onset infection include the following:

- Group B Streptococcus (GBS))
- Escherichia Coli
- Coagulase-negative Staphylococcus
- Haemophilus Influenzae
- Listeria Monocytogenes

Late-onset sepsis occurs at 4-90 days of life and is acquired from the caregiving environment Late-onset sepsis occurs at 4-90 days of life and is acquired from the caregiving environment. Organisms that have been implicated in causing late-onset sepsis include the following:

- Coagulase-negative Staphylococcus
- Staphylococcus aureus
- E coli
- Klebsiella
- Pseudomonas
- Enterobacter
- Candida
- GBS
- Serratia
- Anaerobes
- Acinetobacte

Hyperbilirubinemia: A condition where infants have elevated total serum/plasma bilirubin (TB) levels, which results in neonatal jaundice, the yellowish discoloration of the skin, and/or conjunctiva caused by bilirubin deposition. The major complication of an elevated TB (hyperbilirubinemia) is bilirubin-induced neurologic dysfunction (BIND), which occurs when circulating bilirubin crosses the blood-brain barrier and binds to brain tissue. Therapeutic interventions (ie, phototherapy and exchange transfusion) reduce the TB levels in the blood, which is thought to prevent BIND.

Intraventricular hemorrhage (IVH): A condition where bleeding takes place into the fluid-filled areas (ventricles) inside the brain. Most hemorrhages are mild and resolve with little short-term impact. But some babies may have larger brain bleeding which causes permanent brain injury. Larger brain bleeds may lead to fluid accumulation in the brain (hydrocephalus) over a number of weeks. Some babies who develop hydrocephalus will require an operation to relieve the fluid accumulation.

Gastroesophageal reflux (GER): The passage of gastric contents into the esophagus. GER generally resolves on its own by one year of age.

Anemia of prematurity (AOP): An exaggerated, pathologic response of the preterm infant to the normal decrease in hemoglobin concentration after birth. Typically spontaneously resolves in many premature infants within 3-6 months of birth.

Patent ductus arteriosus (PDA): A heart problem that involves a persistent opening between two major blood vessels leading from the heart. This defect often closes on its own, but if left untreated can cause too much blood to flow through the heart and cause heart failure as well as other complications. Low blood pressure may require adjustments in intravenous fluids, medicines and sometimes blood transfusions.

Necrotizing enterocolitis (NEC): A potentially serious condition, in which the cells lining the bowel wall are injured. Babies who receive only breast milk have a much lower risk of developing NEC.

Other long-term complications may include

- Cerebral palsy
- Impaired cognitive skills
- Vision problems
- Hearing problems
- Dental problems
- Behavioral and psychological problems such as ADHD
- Chronic health issues such as asthma
- Increase risk for SIDS

Characteristics of Babies Born Premature

Babies born prematurely often times do not look or act like a full-term infant. The earlier the infant is born the smaller and less they will typically weigh.

Premature infants have very little fat on their bodies. This makes their skin appear thin, shiny, and transparent. Premature babies will often cry very softly or not at all. They will most likely have trouble breathing due to an immature respiratory system. This can cause abnormal breathing patterns such as periods of fast and rapid breathing or times where the infant will stop breathing for a short amount of time (apnea). Infants born at 28 weeks or less may have eyelids that are still fused shut. Other common characteristics of premature infants include:

- Body hair (lanugo)
- Low activity levels
- Low muscle tone
- Feeding difficulties
- Soft, flexible ear cartilage
- Enlarged clitoris (girls) or small scrotum that is smooth with undescended testicles (boys)

Preventing or Stalling Preterm Labor

If it is suspected a woman is in preterm labor she should seek immediate help from her care provider. A care provider will compare the risks of delivery with the risks of waiting to deliver. They may try to delay the birth with medicine, use antibiotics to treat or prevent an infection, give a steroid injection via the mother to help prepare the baby's lungs for birth, treat other problems causing trouble in pregnancy, or allow the labor to continue because delivery is safer or inevitable. Bed rest may be recommended if preterm labor is suspected.

If a woman has a history of preterm labor she may be given progesterone shots during pregnancy to lower the risk of preterm labor. A cervical cerclage may be used with the use of stitches to hold the cervix shut during pregnancy to stop the cervix from opening early. This could lead to miscarriage or preterm birth. This is not a treatment to preterm labor, but may be used if there is a history of preterm labor.

If cervical changing contractions are occurring, signs of infection are present, or preterm premature rupture of membranes are present medications may be used to delay delivery even if only for a short time. This delay may allow for transport to a hospital with appropriate level of NICU, administration of medicine to speed up lung development in the unborn infant, or administration of antibiotics to treat an infection. Tocolytic Medicines may be used to attempt to stop preterm labor. They include Terbutaline, Indomethacin, Nifedipine, and magnesium sulfate.

Chapter 11

NICU

"Cultivate the habit of being grateful for every good thing that comes to you, and to give thanks continuously."
-**Ralph Waldo Emerson**

What is a NICU

NICU stand for Neonatal Intensive Care Unit. This is a department of the hospital dedicated to newborns who have medical complications or are born prematurely. There are four distinct levels of neonatal care in the United States.

Level I (well newborn nursery): Level I units have the capability to provide neonatal resuscitation at every delivery; evaluate and provide postnatal care to healthy newborn infants; stabilize and provide care for infants born at 35 to 37 weeks' gestation who remain physiologically stable; and stabilize newborn infants who are ill and those born less than 35 weeks' gestation until transfer to a facility that can provide the appropriate level of neonatal care. Required provider types for well newborn nurseries include pediatricians, family physicians, nurse practitioners, and other advanced practice registered nurses.

Level II (special care nursery): Level II units have all of the capabilities of a level I and are also able to:

- Provide care for infants born ≥32-week gestation and weighing ≥1500 g who have physiologic immaturity or who are moderately ill with problems that are expected to resolve rapidly and are not anticipated to need subspecialty services on an urgent basis
- Provide care for infants who are feeding and growing stronger or convalescing after intensive care
- Provide mechanical ventilation for a brief duration (<24 h) or continuous positive airway pressure
- Stabilize infants born before 32-week gestation and weighing less than 1500 g until transfer to a neonatal intensive-care facility

Level II units are required to have pediatric hospitalists, neonatologists, and neonatal nurse practitioners in addition to Level I health care providers. Previously, Level II units were subdivided into 2 categories (level IIA & level IIB) on the basis of their ability to provide assisted ventilation including continuous positive airway pressure.

Level III (neonatal intensive-care unit): Level III units have the all capabilities of level I and level II nurseries, but are also able to:

- Provide sustained life support

- Provide comprehensive care for infants born at all gestational ages and birth weights with critical illness
- Provide prompt and readily available access to a full range of pediatric medical subspecialists, pediatric surgical specialists, pediatric anesthesiologists, and pediatric ophthalmologists
- Provide a full range of respiratory support that may include conventional and/or high-frequency ventilation and inhaled nitric oxide
- Perform advanced imaging, with interpretation on an urgent basis, including computed tomography, MRI, and echocardiography
- comprehensive care for infants born < 32 wks gestation and weighing < 1500 g

Level III units are required to have pediatric surgeons in addition to care providers required for level II (pediatric hospitalists, neonatologists, and neonatal nurse practitioners) and level I (pediatricians, family physicians, nurse practitioners, and other advanced practice registered nurses). Also, required provider types that must either be on site or at a closely related institution by prearranged consultative agreement include pediatric medical subspecialists, pediatric anesthesiologists, and pediatric ophthalmologists.

Level IV (regional NICU): Level IV units are the highest level of neonatal care provided. They have all of the capabilities of Level I, II, and III units as well as:

- Being located within institution with the capability to provide surgical repair of complex congenital or acquired conditions
- Maintaining a full range of pediatric medical subspecialists, pediatric surgical subspecialists, and pediatric anesthesiologists at the site
- Facilitate transport and provide outreach education.

Level IV units are required to have pediatric surgical subspecialists in addition to the care providers required for Level III units.

NICU Staff

The NICU contains many staff that you may regularly see outside of the NICU, but often contains staff specific to the NICU. It can be helpful for parents to learn the different types of providers that will be caring for their infant.

Chaplain: A person who gives spiritual support.

Charge nurse: The nurse who's responsible for making the NICU run well, including scheduling NICU staff. The charge nurse admits your baby to and discharges your baby from the NICU.

Child life specialist: A trained professional who helps children and their families during challenging events. Child life specialists can help older children if they have a brother or sister in the NICU.

Clinical nurse specialist (CNS): A nurse with special training to care for children and their families. The CNS teaches parents about their baby's health condition.

Family support coordinator: A person who provides information, help and comfort to families when their baby is in the NICU.

Lactation consultant: A person who has special training to help women breastfeed.

Medical geneticist: A doctor who has special training to care for people with birth defects and genetic conditions.

Neonatal nurse practitioner (NNP): A nurse with special training to take care of sick babies. The NNP works with the baby's neonatologist, can do some medical procedures and may direct your baby's care.

Neonatal physician assistant (PA): A health care provider who has special medical training to care for sick newborns. The PA works with the baby's neonatologist, does some medical procedures and may direct your baby's care.

Neonatologist: A pediatrician who has special medical training to take care of sick newborns and may direct your baby's care.

Neonatology fellow: A pediatrician who is getting additional medical training to care for sick newborns.

Occupational therapist (OT): A health care provider who helps figure out how well a baby feeds and swallows, and how well he moves his arms and legs.

Ophthalmologist: A doctor who has special medical training in the care of eyes and vision.

Patient care assistant (PCA): A person who helps nurses do things like change bed sheets, feed babies and prepare bottles.

Pediatric cardiologist: A doctor who has special medical training to care for a baby's or child's heart.

Pediatric gastroenterologist: A doctor who has special medical training to care for a baby's or child's digestive system. The digestive system is made up of organs and tubes that digest (break down) food a baby eats.

Pediatric neurologist: A doctor who has special medical training to care for a baby's or child's brain and spinal cord. The spinal cord is the bundle of nerves that carries signals between the brain and the body.

Pediatric pulmonologist: A doctor who has special medical training to care for a baby's or child's lungs.

Pediatrician: A doctor who has special training in taking care of babies and children.

Pharmacist: A person who has special training in how medicines work and the side effects they may cause. People get prescription medicine from a pharmacist. Pharmacists also provide medicines in the hospital.

Physical therapist (PT): A health care provider who looks at any movement problems a baby has and how they may affect the baby sitting, rolling over or walking. The PT helps improve a baby's muscle strength and coordination.

Registered dietitian (RD): A health care provider who is trained as an expert in nutrition. The RD works with the NICU staff to help make sure babies get all the nutrients they need. Nutrients, like vitamins and minerals, help the body stay healthy.

Registered nurse (RN):– An RN in the NICU has special training in caring for sick newborns.

Resident: A doctor who is getting training in a medical specialty. For example, a pediatric resident is getting training to become a pediatrician. A neurology resident is getting training to become a neurologist (a doctor who specializes in treating conditions of the nervous system, which includes the brain, spinal cord and nerves).

Respiratory therapist (RT): A health care provider who cares for babies with breathing problems.

Social worker: A person who is trained to help families cope with their baby's NICU stay. A social worker can give families emotional support and help them get information about their baby's medical condition and NICU care. They also help families find resources and services to help them care for their baby, help families work with insurance companies, and help them plan for when their baby comes home.

Speech and language therapist: A health care provider who has training to help people with speech and language problems. In the NICU, this therapist often helps newborns with feeding problems.

Surgeon: A doctor who has special medical training in doing surgery and other procedures.

Technician: A person who's trained to do things like take blood or X-rays. An x-ray is a test that uses small amounts of radiation to take pictures of the inside of the body.

Helping Parents Cope with Going to the NICU

While most parents understand that the care in the NICU is crucial to the survival of their new baby, but it can still be a stressful and overwhelming for the parents. It is a very different experience than a typical birth where many parents do not get to hold their baby, feed or have the opportunity to start bonding before the baby is taken to the NICU. Time is often experienced differently in the NICU. Parents are facing one day at a time or even one hour at a time with their baby.

NICU babies often need assistance breathing and will have many wires attached to monitor their vital signs. Most NICU babies are not allowed to be held or touched on demand and will not be able to be in the room with the parents. Some families may experience dissociation, PTSD, feelings of inadequacy, hyper-arousal (intrusive painful memories or constant fear), jealousy, any or all stages of grief, and/or anticipatory grief.

One of the first steps to helping parents cope with a NICU stay is education. Parents should become familiar with how the NICU runs and become familiar with their baby's care/preferences. Parents should be encouraged to take part in the care of their baby as soon as possible after birth. They should be encouraged to spend as much time as possible with their baby in the NICU. Premature babies respond to the presence of their parents even if they cannot always be held. Most NICU's encourage parents to do skin-skin care called Kangaroo Care. Parents can feed their baby as soon as care providers give the approval. Some premature babies are not able to nurse from the breast right away and may require feeding through a tube or bottle. In these cases it is encouraged to pump breastmilk to provide to the NICU to feed to the baby. Help parents establish a routine that balances work, home life, and visiting the hospital.

It may be helpful for parents to speak with other parents who have gone through a NICU stay. They should learn common terms, phrases, and problems. The more informed parents are the better they will be able to understand what is happening with their baby and what kind of care their baby is receiving.

Tests, Common Procedures and Immunizations

Many tests are given to premature newborns to detect illnesses and to see if they are developing properly. Some tests are given to check for specific conditions that benefit from early detection. Some of these tests include:

Blood tests: These are the most frequently done in the NICU. The tests check for things like anemia, bilirubin levels, blood sugar level, salt or water imbalance, nutritional needs, or to determine if there is an infection.

Blood gas analysis: This measures the blood gases (oxygen and carbon dioxide). If the infant is very sick this may need to be done several times an hour.

Computed tomography (CAT or CT scan): CT is an advanced form of imaging tissue. It is similar to an X-ray but is able to provide a three dimensional view. The baby will need to go to radiology for this procedure and may need medication to keep still during the test.

Echocardiogram: This is a special type of ultrasound used to study the heart. It can detect structural problems (heart defects) and problems with how the heart works.

Electrocardiogram (EKG/ECG): A test that records the heart's electrical activity. It shows at what rate the heart is beating and if the rhythm is regular. Small, plastic, sticky electrodes are placed on the chest of the baby. They do not hurt the baby.

Hearing test: Also called brainstem auditory evoked response test or BAER. A provider places a tiny earphone in baby's ear and puts small sensors on their head. The provider plays sounds through the earphones, and the sensors send information to a machine that measures your baby's response to the sounds. All babies get this test as part of newborn screening.

Magnetic resonance imaging (MRI): This test uses strong magnets and radio waves to take detailed pictures of the inside of the baby's body. An MRI gives a more detailed view than a CT scan, X-ray or ultrasound. The baby may need medicine to help keep still during the test.

Retinopathy of prematurity exam or eye exam (ROP exam): Providers use this test most often for babies born before 30 weeks of pregnancy or babies who weigh less than 3 1/3 pounds. An eye doctor (also called an ophthalmologist) checks to see if the blood vessels in the baby's eyes are developing the right way. If the doctor sees signs of problems, he checks your baby's eyes over time to see if the condition gets better or if it needs treatment.

Ultrasound: A test that uses sound waves to make pictures of the inside of the body. A provider puts a special jelly on the baby's skin over the area of the body they want to check. Then rolls a small device shaped like a microphone over the area.

Urine test: Tests a baby's urine for certain health conditions. Urine test results can tell providers a lot about the baby's overall condition. For example, test results can tell provider if the baby's getting enough fluid, how the kidneys are working and if the baby has an infection. A urinary catheter is placed in the opening where urine passes out of the baby's body to collect the urine.

Weight: Frequent weight checks help determine growth and development. Providers weigh the baby soon after birth and at least once a day in the NICU.

X-ray: A test that uses small amounts of radiation to take pictures of the inside of the baby's body. X-rays show pictures of the baby's lungs and other organs. If the baby has breathing problems, they may need several lung X-rays each day. X-rays expose the baby to radiation, but the amount is low. Radiation is strong energy that can be harmful to the baby's health if they are exposed to too much.

Nutritional Support: Many preterm babies have difficulty swallowing or have conditions that interfere with oral feeding. As a result, they are unable to get the nutrients they need and require feeding through and IV or feeding tube. This type of nutrition support is called total parenteral nutrition (TPN).

An IV may be placed in the baby's head, hand, lower leg, or umbilical artery. A feeding tube is when a small plastic tube is run through the nose and into the stomach. A small amount of breastmilk or formula is given via the feeding tube. Many times a combination of TPN and feeding tube is used at first.

Respiration Care: Most premature infants need a certain level of respiratory support. The level of support needed typically increases based on level of prematurity. The most common treatments for respiration support include:

- Surfactant replacement therapy
- Breathing support from a ventilator or continuous positive airway pressure (CPAP) machine
- Oxygen therapy

Surfactant Replacement Therapy

Surfactant is a liquid that coats the inside of the lungs. It helps keep them open so that an infant can breathe in air once they are born. Surfactant is given until their lungs are able to start making the substance on their own. Surfactant usually is given through a breathing tube. The tube allows the surfactant to go directly into the baby's lungs. Once the surfactant is given a CPAP device is used. Surfactant often is given right after birth in the delivery room and may be given several times in the days that follow, until the baby is able to breathe better.

Mechanical Breathing Support

Early continuous positive airway pressure is used to help preterm infants. CPAP can be delivered by several noninvasive techniques such as nasal prongs, nasopharyngeal tube, or mask by using a water-bubbling system (bubble CPAP) or a ventilator.

Oxygen Therapy

Infants who have breathing problems may get oxygen therapy. Oxygen is given through a ventilator or CPAP machine, or through a tube in the nose. This treatment ensures that the infants' organs get enough oxygen to work well.

Warmth and temperature regulation: Most preterm infants have little body fat and may be too immature to regulate their own temperature, even in a warm environment. Infants are immediately dried and placed in a radiant warmer after birth. They are then placed in an incubator/isolate until they are able to better regulate their own temperature.

Immunizations: Preterm infants are at an increased risk for experiencing complications of vaccine-preventable diseases. They are less likely to receive immunizations on a typical immunization schedule. The AAP recommends that all medically stable preterm and low birth weight infants should receive full doses of diphtheria, tetanus, acellular pertussis, HAEMOPHILUS INFLUENZAE type b, hepatitis B, poliovirus, and pneumococcal conjugate vaccines at a chronologic age consistent with the schedule recommended for full-term infants.

Common Terminology in the NICU

One of a parents first steps to adjusting to a NICU stay is education. Here is a list of commonly used NICU terminology so parents can become familiar with what is being said between care givers in the NICU.

Adjusted Age: Also known as corrected age, a term used to most appropriately describe children up to age 3 who were born premature. It is calculated by subtracting the number of weeks born before 40 weeks gestation from the chronological age. Example: Baby is 18 weeks old but was born 8 weeks early. Their adjusted age is 10 weeks old.

Anemia: Blood disorder when the level of healthy red blood cells in the body becomes too low.

Apnea: A pause of over 20 seconds in an infant's breathing pattern. Often causes bradycardia.

Aspiration: Inhaling a foreign object, such as food, medicine or meconium.

Bagging: Pumping air or oxygen into a baby's lungs by squeezing a bag of air into a mask placed over the baby's mouth and nose, or through an endotracheal tube.

Bilirubin: A byproduct of the breakdown of red blood cells.

Blood gas: A blood test for determining the pH and levels of oxygen, carbon dioxide and bicarbonate in the blood. The test tells if a baby needs more or less oxygen or other changes in the respirator.

Bradycardia: Slowing of the heart. Often occurs during periods of apnea.

Bronchopulmonary dysplasia (BPD): Changes in a baby's lungs following severe respiratory distress in premature infants who have been treated with oxygen and mechanical ventilation.

Catheter: A hollow flexible tube for insertion into a body cavity, duct or vessel to allow passage of fluids or distend a passageway. Its uses include the drainage of urine from the bladder or insertion through a blood vessel into the heart for diagnostic purposes.

Central Venous Line: A narrow tube that is placed into a large blood vessel and passed into the opening of the heart. It is used to receive medicine, fluid, and to draw blood.

Complete Blood Count (CBC): Blood test that looks at the number and type of white blood cells, the concentration of hemoglobin, the percentage of blood volume consisting of red blood cells (hematocrit), and the number of platelets.

Continuing care nursery (CCN): A nursery that eases an infant's transition to home. **Continuous positive airway pressure (CPAP):** A method in which low pressure is kept in the airways to keep the air sacs in the lungs open and make it easier for a baby to breathe. The baby does all the breathing on his or her own.

Cyanosis: Bluish coloration of the skin, lips or nails that happens when there is not enough oxygen in the blood.

Echocardiogram: A method of recording a picture of the heart using the echo of sound waves that can be used to evaluate the structure and function of the heart.

Endotracheal tube (ETT): A plastic tube placed through the nose or mouth into the trachea (windpipe). The tube allows oxygen to be delivered to the lungs by a respirator.

Extracorporeal Membrane Oxygenation (ECMO): In infants, this machine is usually used to allow the lungs to rest and recover from disease or medical conditions. ECMO is similar to the heart-lung bypass used in the operating room but is used for longer period of time.

Extubate: Removal of an ETT

Gavage feeding: Feeding through a small plastic tube passed through the nose or mouth into the stomach.

Gestational age: Age of a baby in weeks, starting from the beginning of pregnancy.

Glucose: Sugar in the blood used for energy.

Hematocrit ("crit"): The percentage of red blood cells in the blood.

Hemoglobin: The component of red blood cells that carries oxygen. Used as a measure of anemia.

Hyperalimentation (HAL): Administration of nutrients into a vein. Used with infants who cannot be fed breast milk or formula.

Incubator/Isoette: A type of enclosed bed for an infant who is not mature enough to maintain his or her temperature in an open bed.

Induced hypothermia: A treatment that reduces a baby's core temperature. The treatment is thought to provide some protection to the injured brain of an infant who has suffered from a traumatic event before or during the birth process.

Intralipid: A white, high-calorie solution given through a vein to provide fat for babies who cannot be fed breast milk or formula.

Intravenous (IV): A thick, plastic tube placed in a baby's umbilical artery and/or vein (UA or UV line) or in a vein in the head, hand or foot. It is used to take a blood sample and/or to give fluids and nourishment.

Intubation: The procedure of inserting a tube through the mouth or nose, down the throat, and into the trachea or windpipe of an infant who may have difficulty breathing, or may be at risk of stopping breathing because of illness, surgery, or other medical problem.

Jaundice: A yellow color of the skin caused by too much bilirubin in the blood. Usually, this is a temporary condition.

Kangaroo Care: Holding a baby against ones's bare skin chest, so there is skin-to-skin contact.

Meconium: A baby's first stool, which is dark green or black.

Nasogastric (NG) / orogastric tube: A small plastic tube placed in the stomach through the nose or mouth. It can be used to feed a baby, give medicines or remove air from the stomach.

Oscillator ventilator: A highly specialized breathing machine.

Oxygen: A colorless, odorless gas that makes up 21 percent of the air we breathe. Sick or premature babies often need extra oxygen.

Oxygen hood (OXY-Hood): A clear plastic box with a tube attached that is placed over the head to deliver oxygen to a baby.

Percutaneous Line (PICC): A long catheter paced into a surface vein, with the catheter tip extending farther into the body into a large vein.

Persistent pulmonary hypertension (PPH): A condition in which the blood continues to flow through an infant's heart the way it did in the womb. This condition causes cyanosis and extreme instability of the body.

Phototherapy: Treatment for jaundice using fluorescent lights. Pneumonia: An inflammation of the lungs.

Pneumothorax: The presence of air between the outer lining of the lung and the chest wall, which causes the lung to collapse.

Pulse oximeter (pulse ox): A machine that measures the amount of oxygen bound to the hemoglobin molecules in the blood through a small probe wrapped around an infant's hand or foot.

Radiant warmer: An open bed with an overhead warmer that helps keep a baby warm. **Respirator (ventilator):** A machine to help with breathing.

Tachycardia: Fast heart rate.

Tachypnea: Fast breathing.

Transcutaneous monitor (TCM): A monitoring device placed on the skin to record blood oxygen levels.

Ultrasound: A method of taking pictures of body organs such as the brain, kidney or liver.

Vital sign: An indication that a person is alive. Vital signs include temperature, heart rate, breathing rate and blood pressure.

Family Centered Approach

A family centered approach in the NICU involve parents as collaborative partners and essential members of the high risk NICU team. Parenting is a developmental process in which parents learn to care for their infant. Being a part of the care team in the NICU will enhance the development of parental competence and empower families to care for their infants in the NICU and at home. Families can learn what activities they may be able to assist with in the day to day of their baby. This may include assisting in changing the tubes in the CPAP device, taking baby's temperature, changing baby's diaper, changing baby's outfit, or just being present to talk with the baby while staff perform clinical duties. Some hospitals have overnight rooms in the NICU where parents can stay the night with the baby in the room with them.

Kangaroo Care: Kangaroo care is the process of initiating skin-skin contact between the parent and newborn. It has been well established that Kangaroo Care is one of the most important, nurturing gifts parents can give to their baby. Parents provide kangaroo care by placing the baby directly on the skin of the bare chest and covering with a blanket.

Special Considerations in NICU

Just with any other part of the hospital there are rules and regulations the NICU has to follow and has to have visitors and parents follow. Some aspects about the NICU may make coping with the stay harder. Here are some additional considerations to think about.

Visitation: Parents and visitors will be issued a NICU badge. NICU's are closed units and require authorization to enter. Many NICU's will limit the number of visitors that can be in the NICU and most only allow two family members to be present at the bedside of the infant. Siblings may not be permitted to visit the NICU depending on age requirements of the hospital. Additional visitation restrictions may be placed during flu season.

Confidentiality/ Close Quarters: Families will need to remember the NICU is home to other infants and families. Many NICU's have an open layout with curtains separating one infant from another. This can feel like a lack of privacy to some families. Families are encouraged to use quiet voices at all times, keep their cell phones on silent, and avoid comparing progress from one infant to another. Each family has their own unique set of experiences they are going through. It is important to be respectful.

Being able to leave for home before baby is ready to come home: This situation is very common. Most women will be able to leave the hospital after a short stay of 24-72 hours depending on the type of birth they had (vaginal or cesarean) and their current health status. A long stay in the NICU may not be directly related to their health status. Some premature babies just need more time to grow and develop before they are ready to be discharged. Some near term infants may need a few days while some younger gestation babies may need to stay for a few months.

Coming home from the hospital without a baby to bring home can be an overwhelming experience for the family especially the mother. Families should have extra support at home and find a way to visit the hospital often to continue the bond with their baby.

Medical decisions regarding sustaining life or ending care: Sometimes a family will be faced with the impossible choice of continuing life sustaining care. Parents should be fully educated on all options so they may be able to make an informed decision to the best of their ability. The emotional and financial burdens on the family are often underemphasized. The decision to withdrawal life support is very painful, leaving parents with feelings of loss, emptiness, guilt, anger, and pain. It is important for parents to be involved in palliative care that emphasizes quality of life while alleviating the symptoms of medical conditions and their treatments. It is important to reassure parents that it is normal to feel uncomfortable.

Transition Home From NICU

When infants are born before their due date or with health problems, families often need help managing their baby's health care after leaving the hospital. One of the first steps to care when transitioning from NIUC to home is to select a primary care provider. This may be different if the infant has disabilities or special conditions.

Choosing a primary care provider: The family will need to visit a primary care provider within the first week of leaving the hospital. Parents should plan ahead to avoid the pressure and frustration of finding a care provider right before their baby is discharged. Many NICU's will not discharge an infant until they have an appointment with a primary care provider for a follow up. NICU staff can be a great resource in location a primary care provider. Parents should keep in mind where the primary care provider conducts office visits if it should be close to the home or work, if they accept their current health insurance and if they are accepting new patients.

Insurance: Most insurance companies will allow billable items to be covered under the parents insurance until the baby is added to the insurance plan. Most companies require families to add a new baby to an existing insurance plan within 30 days. If the parents do not have health insurance they may qualify for Medicaid or other state funded programs to help cover costs.

Parental education: There are many topics parents will need to become familiar with when learning to care for a baby coming home from the NICU. Parents should know all of the following before baby is discharged from the hospital. Some of these topics are more general to all babies while others will be specific to their baby such as medications.

- Hand washing-preventing infection
- Behavioral cues
- Basic infant care
- Feeding
- Sleep and wake cycles
- Sleeping position- SIDS
- Stool and urine patterns
- Signs of illness- when to call 911, when to come to the hospital
- Medication and equipment- medication doses, side effects
- Premature Babies Immunization Schedule
- Home and car safety
- Visitors and outings

Parents should work closely with the NICU staff and primary care provider to evaluate any unresolved medical problems. They should develop a home care plan that may include items like managing child breathing problems at home. When evaluating milestones parents should remember corrected gestational age. Premature babies often to not hit milestones at the same pace as full-term babies. They tend to be smaller on the growth charts for the first few years of life. This s is normal.

Chapter

Birth Professional Grief & Self-Care

"As you grow older, you will discover that you have two hands, one for helping yourself, the other for helping others."
– Maya Angelou

The Birth Professional

Close personal relationships often develop between birth workers throughout the time they provide services. When our clients experience loss we may experience an overwhelming sense of grief and loss. It is important to address this grief so it does not begin to affect our lives in other ways. When we allow our grief to be recognized, addressed and supported, we cope by finding meaning in the loss.

As birth workers we often experience compassion fatigue if we are not careful. Compassion fatigue is a term used to describe the physical, emotional, and spiritual exhaustion resulting in caring for clients and witnessing pain, suffering, and loss. This is often associated with the inability to provide compassionate care and a decrease in the quality of care provided.

Consequences of Unresolved Greif and Compassion Fatigue

Symptoms of cumulative grief may include physical illness, substance abuse, suicidal thoughts, apathy, poor self-esteem, depression, and anxiety. The effects of cumulative grief may cause birth workers to detach emotionally, or overinvest in clients' lives, which may lead to the development of compassion fatigue. The effects of compassion fatigue may include extreme weariness, poor performance, and multiple physical complaints. Emotional effects include lack of enthusiasm, depression, desensitization, irritability, feeling emotionally overwhelmed, and loss of ability to enjoy life. Physical complaints may include gastrointestinal disturbances, headaches, weight gain, and sleep disturbances. Emotionally exhausted caregivers may experience symptoms similar to post-traumatic stress disorder, such as recurrent recollections, distressing dreams, and anxiety, as well as physical symptoms such as irritability, difficulty concentrating, and insomnia.

Coping With Grief and Compassion Fatigue

Many of the same strategies for preventing and managing the effects of cumulative grief also are recommended to prevent and treat compassion fatigue. Birth workers should strive for a healthy for work-life balance and engage in frequent self-care. Birth workers should find activities and practices that replenish, comfort, and rejuvenate the spirit such as exercise, family or religious activities, journaling, massage, craft making or whatever promotes rest and comfort. Access to support groups including peer to peer support is an important aspect of self-car. Holistic practices, such as yoga, tai chi, meditation, Reiki, relaxation exercises, and music, are effective self-care strategies and may help birth workers rejuvenate and self-heal. Birth workers may feel isolated and unable to share feelings of loss when they experience a client loss. Opportunities to discuss emotions may help birth workers realize that these feelings are common and expected Birth workers should acknowledge the importance of education in the areas of identifying, combating, and treating compassion fatigue. Communication skills, particularly those that help birth workers learn how to ask for support and handle conversations with clients and families, are essential.

The first step is to recognize and acknowledge that grief is present. Birth workers should then seek their own way to work through their grief with support. This support may come from your family, close friends, co-worker, or peers. There are many online outlets to find support if there are no local resources for you. Then birth workers should continue to engage in self-care on a regular basis to help prevent compassion fatigue.

Self-care

While self-care may seem intuitive sometimes we work so hard to put our clients first that we neglect ourselves both while with our clients and while we are away from them. In western society self-care is often neglected and not encouraged. Birth workers should take time to plan a routine of self-care and practice it every day. It will not only help you in your work, but in your day to day life as well. The following are suggestions on what to add into your personal self-care routine:

- Eating healthy
- Getting plenty of sleep
- Staying active
- Form a support team
- Get outside frequently
- Keep a journal
- Get some "me time" (massage, nails done, spa trip)
- Keeping work and home life separate
- Create boundaries with clients
- Have backup- back up doula, backup childcare
- Spend time with your partner doing something special
- Ask for help when you need it

Parting Thoughts

Loss is still a taboo subject worldwide. Women of all walks of life from all different countries experience similar feelings of shame and guilt. Sensitivity and empathy go a long way, even when you don't know what to say.

Loss is a part of many families journey. When we become birth professionals we do not expect loss to be part of our journey. The real truth is; it **is** are part of our journey. A part that has been silenced. A part no one wants to talk about. It is our duty to open the doors of communication.

Though the subject is not one full of joy and happiness, we can take peace in knowing and understanding. Knowing **we** are prepared to support others. Knowing **we** do not have to suffer in silence. Knowing **we** can encourage women from all walks of life to share their stories.

We know how to save more babies worldwide by improving access to prenatal care, continuity of care with a midwife, and the use of community care where possible. Integrative care that includes prenatal screening and adequate fetal heart monitoring during labor could save millions of lives.

Front line birth professionals are part of the integrative care team. As front line birth professionals we spend the most time with our clients. It is our job to support them in preventative education as well as providing support during and after a loss.

Imagine a world where women were not afraid or ashamed to share their story. If people shared with their communities with a sense of care and understanding. What if we all started a movement to build a society where we can all share our stories and could grieve for our loss instead of mourning in silence? Let's be the difference we want to see in the world. Share your story or be an ear to listen to someone else's. Include bereavement conversations in your own birth business.

Anyone who wants someone to share their story with or needs advice on how to support someone else during loss know that I am here. Send me a message, write me a letter, friend me on Facebook.

As we part ways I leave you with one finial quote.

"There is no footprint too small it cannot leave an imprint in this world"
--- **Unknown**

With Passion and Power,

Resources

Now I Lay Me Down to Sleep: provides photography services for stillbirth and infant loss. https://www.nowilaymedowntosleep.org/

Faces of Loss: a place to share your story and connect with others who have survived loss. http://facesofloss.com/

Compassionate Friends: an organization that provides in person support groups for bereaved parents.
https://www.compassionatefriends.org/

Midwives Coping With Loss and Grief: a book for midwives about miscarriage, stillbirth and infant death.
https://www.amazon.com/Midwives-Coping-With-Loss-Grief/dp/1846193885

Still Standing Magazine: a resource for parents.
https://stillstandingmag.com/

Mending Invisible Wings: a creative workbook for those working through pregnancy loss.
https://mendinginvisiblewingsblog.wordpress.com

SHARE Pregnancy & Infant Loss Support: offers support groups and resources for families surviving a loss. http://nationalshare.org/

The Miss Foundation: counseling, advocacy, research and education for grieving families. https://missfoundation.org/

Still Birthday: resource regarding pregnancy loss for both parents and birth professionals.

TAKE YOUR NEXT STEP

Join Birthing a Business Education Services Community

Imagine author Julie Banas or one of her Certified Instructors leading you through a transformational process where you journey through your potential for a sustainable birth business.

Imagine finding clarity by using simple steps and strengthening your core potential.

Join our community of birth professionals who have found less stress, more freedom and a bigger impact so they can spend more time doing what they love with who they love.

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What's the cost of not living to your true potential?

BRING JULIE INTO YOUR COMMUNITY OR BUSINESS

BIRTH PROFESSIONAL
AUTHOR | SPEAKER

Julie knows the importance of building a sustainable birth business. Building a solid foundation sets you up for success. This includes business skills and quality birth professional training.

Whether you are just starting out or you are a seasoned birth professional, building a solid foundation is a must for success. Julie's authentic approach combined with superb content positions her as a top choice for many birth businesses and organizations. She customizes each message and training to achieve and exceed the needs of her clients. Choose from these courses and more:

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The BABES Team

Certified Trainers, Educators, and Mentors

WE CAN'T CHANGE THE WORLD ALONE
WE NEED A TEAM

We call it the BABES tribe.
If you're looking to join a team that helps other birth professionals realize their true potential and discover their Why, consider joining The BABES Team.
Do what you love and get paid for it.

Host a workshop or become a BABES certified Trainer.

If our team fits your style then we'd love to chat with you. There's a spot waiting for you in our lineup.

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