Perinatal and Infant Loss:
A Resource for Orthodox Christian Pastors

The Committee for Pastoral Practice

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Preface

This resource is an attempt to bridge the gap between what our Church teaches about the child in the womb—beloved of God, bearer of his sacred image—and what is often practiced when one dies. Many believe that the traditional miscarriage prayers do not strike the right pastoral tone, and what is left is a gaping hole where something could be said or done.

We cannot say "if" a loss occurs, because miscarriage, stillbirth and infant death happen more often than most people realize. Almost one in five pregnancies will end in miscarriage, and in the United States alone, about 25,000 stillbirths occur each year. That's enough to touch nearly every parish—and every priest—in this country.

That is where this booklet comes in. It is our hope that this book will equip pastors to better minister to families in these situations, that it will put an end to the awkward silence that sometimes surrounds these events, and that no woman will ever have to say, "I told my priest about it, and he said nothing."

What you hold in your hands is a resource that offers you a variety of suggestions about what you can *say,* what you can *do*, and what you can *pray*. We hope that you will find it helpful as you continue to reach out to those you serve, and that this resource will equip you to speak into this heartbreak with knowledge and love. Although life is sometimes shorter and more wounded than we could have imagined, life is still bigger than death, and there is always something we can do.

As St. John Chrysostom said in his Paschal Sermon:

"O Death, where is your sting? . . . Christ is risen, and life reigns."

Life reigns!

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TABLE OF CONTENTS

Introduction: Perinatal and Infant Loss 1

Pastoral Care for Those Facing Pregnancy Loss or Infant Death 2
- **Pregnancy Loss** 2
- **Individualized Care of the Grieving Parents** 2
- **Understanding the Grief Experience** 3
- **Making Decisions** 4
- **Pastoral Care of Presence** 5
- **Unique Aspects of Stillbirth** 7
- **Unique Aspects of Life-limiting Diagnoses** 8
- **Pediatric Palliative Care** 8
- **Naming the Child** 9
- **Paying attention to Dads** 9
- **Paying Attention to the Marriage** 10
- **Attending to Siblings** 10
- **Parish-wide Pastoral Care** 11
- **Liturgical Remembrance Opportunities** 11
- **Memorial Gardens** 11
- **Dedicated Cemetery Space** 11
- **Health Ministries** 11
- **Two Key Points** 12
- **What Not to Say** 12

Before You Get the First Call 13
- **Laws and Regulations** 13
- **Starting Points** 14

Medical Terminology for Pastors 16
- **A Glossary of Terms and Procedures** 17
- **Medical Procedures** 19
- **Infant Loss at Various Stages of Pregnancy** 19
- **Life-Limiting Diagnosis** 20
- **Myths and Misinformation** 20

Pastoral Care and Advocacy – A Summary 22

Resource Materials on Infant and Pregnancy Loss 23

Prayers 25

Introduction: Perinatal and Infant Loss

Some sources estimate that up to 20% of confirmed pregnancies end in miscarriage or stillbirth. One recent article states "In the United States, an estimated 70 stillbirths occur each day, on average 25,000 a year…"[1] Given these statistics, the question is not "if" miscarriage will touch the women and families of Orthodox parishes, but "when". This booklet is intended to help clergy and caregivers within the community of the Orthodox Church better understand and prepare to help couples, especially mothers, address the emotional and spiritual needs that will almost certainly surface.

It is not uncommon for mothers that have miscarried to suffer a sense of loss that leads to depression and isolation from family and friends, including their parish family, at a time when they need emotional and spiritual support the most. Very few clergy are well prepared or equipped to respond constructively at a time when pastoral care is most needed. At a time when grieving parents need to be heard the most, they retreat into a painful silence because those close to them simply do not understand the depths of their grief.

It has been said the Church is both our mother and a hospital. It is the place where one should be able to receive healing grace through her sacraments and ministries. The pastor is key to a sound, Orthodox response. As the one who has been set apart to make Christ the Divine Physician present, his role in leading grieving and wounded parents back to spiritual and emotional health is critical. We offer this booklet to the Orthodox pastor as a resource in understanding what perinatal and infant loss are and to suggest ways he can help parents and families negotiate what can be a maze of confusing emotions, medical and legal issues, and, finally, offer the comfort and care that are to be found only in and through the liturgy of the Church.

[1] Kelley and Tinidad, BioMed Central, 2012, "Silent loss and the clinical encounter…"

Pastoral Care for Those Facing Pregnancy Loss or Infant Death

Pregnancy Loss

Pregnancy is a time to look forward to the arrival of a new child with excitement and joyful anticipation. Many women have been anticipating this event since childhood. Feelings of joy and anticipation are quickly replaced with shock, sadness and confusion when couples suddenly find out their child has died.

Death is a painful and confusing experience, a topic we are naturally inclined to avoid, and the death of a child is a particularly intense experience. Miscarriages (the death of a baby before the 20th week of pregnancy, considered non-viable), stillbirths (the death of a baby 20 weeks or older who died *in utero* or during the birth process), and life-limiting diagnoses (the baby is diagnosed with an abnormality or set of abnormalities that will lead to death *in utero* or shortly after birth) are terms to describe perinatal loss - the death of a child during pregnancy or following birth.

It is estimated that up to one in four women will lose at least one pregnancy in their lifetime. Miscarriages and stillbirth are more common among mothers who are very young or who are older and are more common in pregnancies with multiples (e.g., twins, triplets, etc.). Chromosomal anomalies are most often implicated in first-trimester miscarriages (first three months of pregnancy), but in the vast majority of cases the cause is not known.

Individualized Care of the Grieving Parents

At the heart of caring for those suffering this type of loss is the recognition that each woman will have a unique grief experience depending more upon her particular person than on other factors. While it is tempting to compare different types of losses and assume that the farther along in the pregnancy the death occurs the greater the grief, this is neither accurate nor helpful. In fact, each woman will respond in a unique way and it is for the pastor to attend to each woman's particular grief experience. Independent of when in the gestational process the death occurred or how many other children she has or may have in the future, some women will mourn for a time and integrate the death into their lives moving forward, while others will struggle with intense grief, self-blame and depression. For some women, previous and future pregnancies will provide comfort and consolation, while for other women they will serve as reminders of the painful experience of death. In all cases, a responsive pastoral presence is critical in assisting parents through the grieving process.

A mother's grief can be exacerbated by the confusion, ignorance, and misguided love of family and friends. Particularly when the death occurs early in the pregnancy, if the mother is young, or has other children, it is easy for family and friends to minimize, dismiss, or misunderstand the mother's grief. This serves to intensify the pain and sense

of isolation and grief common to this loss. The experience can be traumatic for a mother when the pastor, or "the Church," makes similar mistakes. Typically, only women (and their husbands) who have experienced this type of loss understand the nature of this kind of grief. However, anyone can take a moment to learn about this experience and follow a few simple guidelines for caring for those who are bereaved.

Understanding the Grief Experience

Sometimes, the miscarriage occurs early in the pregnancy, when only the parents know they are expecting. Other times, family and friends are anxiously awaiting the birth and thus become part of the grieving process. Although some mothers have 'a sense' that something was not right with their baby, typically the death is sudden and unexpected. Parents characteristically react with shock, disbelief, sadness and a profound sense of loss and grief. Sudden loss of a loved one, even in the womb, is an intense and disorienting experience, affecting a person's ability to focus or make decisions. Perinatal death can be an extremely painful, frightening, and lonely experience. Some mothers wonder if they will be able to bear the pain. Some have described the experience as though, "the bottom falls out of their lives." These are normal and appropriate responses. Parents, and mothers in particular, should be allowed and encouraged to share or express the wide array of feelings they are experiencing.

The death of an unborn child represents not only the loss of a life, but also the loss of the hopes, dreams and expectations of the parents. Expectant parents have been preparing and looking forward to taking the new baby home from the hospital, caring for and raising their child for a lifetime. In a real sense, the death of an unborn child "changes everything." It takes time for parents to adjust to the variety of related losses associated with the painful reality of death and find their way forward.

It is easy for a woman to feel guilty -- that she is, somehow, to blame for what has happened.
A mother might wonder if she did something to cause the death, or could have done something to prevent it. She might feel like she has failed, or has let others down by failing to carry the child to term. Friends and family might hold erroneous beliefs or superstitions about these types of deaths (see the section, "Myths and Misinformation").

The loss of a child might represent the loss of a woman's identity as a mother. Or, if she was ambivalent about the pregnancy, her sense of guilt may be compounded. The fact is, it is nearly impossible for a mother to cause a miscarriage. Even so, it is common for a mother to feel responsible, or to wonder about this.

Mothers continue to experience the effects of pregnancy loss with subsequent pregnancies. Mothers can have heightened anxiety and concern during future pregnancies. Some mothers might feel guilty. Additional miscarriages, naturally, heighten the grief; successful pregnancies can provide comfort, although the memory of earlier losses will remain.

It is natural to long for, or search for, some reason for the death. Mothers are left wondering why their baby died. Often, the actual cause of the miscarriage, or perinatal death, is not known. Death, although natural in a fallen sense, is considered, from an Orthodox perspective, to be an unnatural event. Confusion around why this happened, coupled with the grief of a loss, can leave a woman disoriented and overwhelmed emotionally.

However, when a woman asks, "Why?" she is not asking, "Why is there death?" for which we have a theological answer. Death entered the world through sin (Romans 5:12). She is, in fact, asking, "Why has death entered my experience of life?" More specifically, she is sharing that she is confused and in pain because she was not expecting to encounter death in this fashion. We have a response to that. Our response is to offer a peaceful, prayerful, listening presence.

The inability to get answers can confuse or anger the parents. While miscarriages are relatively common, this fact provides little comfort. To a mother, the death of an unborn child represents a major, life-changing event. Rather than trying to normalize the loss with statistics, it is better to help a mother express her personal experience of the death. The fact that this is a relatively common experience should mean that pastors are prepared ahead of time to support and guide a mother through the experience.

The grief process can be complicated by the physical and hormonal changes associated with pregnancy as well as by previous losses or trauma a woman has experienced in her life. If a woman has a history of depression, she will be at risk for having a new depressive episode at this time. Additional attention and care will be needed to help these vulnerable mothers process this new experience of loss.

Making Decisions

Not limited to simply hearing the news that their child has died, parents must make decisions about how they will proceed with the delivery process and burial of the unborn baby. Unless a medical emergency is involved – in which case, decisions are straightforward -- mothers are asked to make choices about what to do next. Typically, if the child dies before 12 weeks (the most common time to miscarry), no intervention is required to deliver the child. After 12 weeks, the process of loss may include the need or recommendation for the mother to have a surgical procedure to end the pregnancy. When the baby has not died but is not expected to survive labor and delivery, the mother is often asked to consider terminating the pregnancy.

Surgical procedures include dilatation and curettage (D&C) and dilatation and evacuation (D&E). These might be done regardless of whether or not the unborn baby is still living. Other options include induction of labor and simply letting the pregnancy proceed to its natural conclusion as long as the mother's health is not at risk.

When mothers choose to let their pregnancy progress naturally they must endure the normal physiologic changes of pregnancy as well as the mistaken congratulations of those who do not know that the baby has died or will likely not survive birth. When specifically requested by the parents, pastors may offer guidance to them as they make decisions about terminating their pregnancy.

The decisions made by the mother during this vulnerable time will have an impact on her grief and, if made hastily, may lead to prolonged suffering and regret as the years pass. Mothers who request a natural delivery and to hold the body of the child, however painful the moment may be, report being grateful for how this helped in the grieving process. Pastors should encourage the parents, even if it is difficult, to enter into the full experience of the birth. If not a part of the hospital protocol following the loss of a baby, pastors can encourage parents to hold and spend time with their baby, take photos and gather mementos like hand and foot prints and locks of hair, and even bathe and dress their child. While it is painful in the moment, it will be invaluable as the parents reflect back on this loss later in life. Your pastoral presence at this painful time will help the parents to properly grieve this tragic loss.

Attending to the body of the child, regardless of the time at which the loss occurred, can complicate or facilitate the mourning process. After delivery and the initial moments of mourning, parents are asked to decide what they would like to do with the remains. If they choose to have an autopsy performed, it will be unlikely that they will be able to inter their baby. Many hospitals offer parents the option to bury their infant, making it possible for them to take their baby home for burial if the loss occurred early in pregnancy. When the loss occurs later in pregnancy, burial of the baby may require the services of a funeral director. (Please see the section titled, “Laws and Regulations”) Hospital chaplains are available to help parents navigate through the required paperwork and phone calls. Pastors may help the couple decide whether or not to have a public or private, formal or informal service and burial. When there are siblings involved, pastors may be able to help the parents find opportunities for the children to participate in the process as a way to recognize their shared experience of the loss.

Pastoral Care of Presence

The role of the pastor is to be a peaceful, prayerful, listening presence throughout the entire process of loss. Parents need to know that their pastor is available and will help them no matter the stage of pregnancy. Pastors cannot answer many of the questions that arise, such as why things happen as they do. A pastor cannot provide medical care but can provide the essential emotional and spiritual care required at this time. A pastor can give the grieving mother permission to feel and express whatever she is experiencing, and to provide comfort by his silent, prayerful presence. The pastor should resist the temptation to provide theological answers to why things happen the way they do, because, particularly early on in the process, a woman is not asking for an answer but is seeking emotional support. Your prayerful presence will communicate the fullness of God’s love and providence more than words.

Drawing close to a grieving mother can be a difficult pastoral experience for the pastor, particularly if he sees his role as alleviating suffering or solving problems. The intensity of the grief can tempt a pastor to try to resolve the grief, and can distract him from his role as a peaceful, prayerful presence. Pastors are encouraged to resist the temptation to do anything more than remain close and prayerful, and trust that God's love, in God's time, will provide the necessary healing.

Some pastors find it helpful to understand the grief process as going through a series of stages- denial, anger, bargaining, depression, and acceptance. This understanding can help the pastor be prepared for the types of feelings a woman might have. In another sense, coping with grief and loss is a process of grieving the loss while at the same time adjusting to life in a new way. Death can change everything for parents. Parents must grieve the death of their child as well as the loss of their hopes, dreams and expectations, while at the same time moving forward, adjusting to their new lives that have now been touched by death. Part of this process of adjusting to a new way of life involves making sense of the death and finding meaning in life. If our identities are attached to parenthood and our hopes were attached to having a child, then the death of a child, and the fear of ever being able to have another child, can disrupt how we understand a meaningful life.

Primarily, caring for someone experiencing the loss of a baby involves allowing the parents to express the various aspects of their experiences, to "confess" how they have experienced this death as they adjust to a life that has been marked by death. Pastors assist parents in this process by being a listening presence while the grief is acute and, over time, guiding the parents to rethink issues related to life, death, God, and the world. As the parents adjust to what it means to live in the face of death, the life in Christ offered by the Church provides us with a pathway forward. Rather than providing simple answers to an acutely grieving parent, pastoral care for the bereaved is a process of walking with the parents as they slowly adjust to the reality of the loss. As we care for the bereaved, the experience of loss can be an opportunity for connecting our lives closer to Christ and His Church, and to reorient our lives to Him. This can only be done if we, first, attend to the grief and loss rather than ignoring, avoiding, or dismissing it.

Finally, the goal of the pastor is to help the mother integrate the loss into her life moving forward -- not to help her move on, or "get over the loss." While the severity of the pain tends to diminish over time, there is no point when a mother will be "finished" grieving. It is important for the pastor to follow-up with the parents and provide opportunities for parents to remember their child and continue to share their pain and struggles. Friends and family, as well as pastors, might be tempted to avoid mentioning the loss or to 'not bring up that painful experience,' particularly after the parents give birth to subsequent children. However, mothers have a natural instinct to remember their children. It is an act of love to allow the mother to remember her child and to share her ongoing grief for the loss. It is useful to have regular times of the year when the pastor can remember those in the community who have experienced perinatal loss. Although we do not pray for the souls of the unborn as we do for those who are born and then die, the grief of the parents

continues. It is pastorally important and theologically correct to remember, as a community, these losses as well.

Unique Aspects of Stillbirth

Whether the death occurs early or late in pregnancy or is the result of a birth accident or fetal abnormality, it is wise not to compare the different types of loss. Each parent's experience is unique and requires an understanding of his or her personal response to the death. In addition to the possible emotional experiences already discussed, parents who suffer a stillbirth experience additional complications and challenges. Learning of the death of a baby late in gestation is usually unexpected and comes as a shock, especially when the pregnancy has been progressing normally for months. Few mothers realize how common this is, and most never think that it would happen to them. When a baby dies at the time of birth, with no prior warning, the excitement of birth is replaced by utter devastation. The parents may hold a perfectly formed baby who died as a consequence of a physiologic accident, thus compounding the trauma of the tragic death.

Sometimes, the grief process begins without warning, when the mother senses something is wrong, seeks medical attention and then learns that her doctor cannot detect a heartbeat. Before the parents can adjust to the shocking news, they are faced with the emotionally tormenting process of deciding how they will deliver their dead baby and care for the body. Often, parents are urged to make decisions quickly, based solely on the advice of their doctor, without adequate time to reflect and absorb information. If the baby dies during labor, parents may be wholly unprepared for the death. If they have known that their baby was dead prior to the onset of labor, they may experience renewed anguish as the hoped for miracle of a live birth is replaced by the reality of death. In the hospital, the grieving mother will be surrounded by the sights and sounds of happy parents and healthy babies. She will experience all of the physiologic changes of the mother who has delivered a living baby, further deepening her sense of pain and loss. This serves only to exacerbate the grief, pain, anger and confusion associated with the parents' great loss. Now the couple, who had anticipated a happy homecoming, must leave the hospital with empty arms.

Medical professionals oftentimes are focused on providing information and determining the causes of the stillbirth. Physicians and medical personnel have more training delivering babies than providing grief counseling and emotional support. While some hospitals go to great lengths to support the bereaved parents, others are not prepared to offer the sophisticated emotional support needed by the parents. The provision of emotional support by the pastor, both at the immediate time of death and during the ongoing process of grief, is critical for parents. Because the parents are experiencing intense grief and even shock, it can be difficult to hear or to understand what is happening, to make decisions, to listen to advice, and to navigate the process. Particularly with decisions regarding the care of the child's body, the pastor's assistance can be extremely important. Uninformed decisions in the moment lead to regret and complicated

grief later on. Please refer to the section, "Before You Get the First Call" below on how to be prepared to assist couples with the logistics of this process.

Mothers who suffer stillbirths are at risk for depression. It is important for the pastor to remain involved following the delivery and burial, to continue to assist the parents and to monitor their well-being. If the mother experiences severe depression it is important to include psychological counseling in the healing process. No matter how many additional professionals are involved, the pastor serves a critical role in ongoing care.

Unique Aspects of Life-limiting Diagnoses

With the development of technology has come the increased ability to make prenatal diagnosis of problems in the baby. In the past, these births would take parents by surprise. With routine prenatal testing, parents usually learn early in pregnancy that their baby has a defect. Once a problem has been identified, parents are confronted with the need to make a decision about continuing the pregnancy or terminating it. Though rare, genetic and structural abnormalities that are incompatible with life present a devastating loss for the parents. These include Trisomy 18 (a genetic abnormality) and anencephaly (absence of full cranial development). Problems such as congenital heart disease and Down's syndrome are not incompatible with life and individuals with these conditions often live fulfilling lives.

Once informed of the diagnosis that a baby is likely to have special needs, will be unable to live outside the womb or will die shortly after birth, parents often feel pressured to have labor induced or to consent to surgical termination of the pregnancy. Well-meaning physicians may encourage procedures that are not medically necessary but are recommended to "minimize parental grief" or "end the inevitable."

Parents should not be rushed to make decisions. Instead, they should be advised to consider their options after much thought and with the prayerful guidance of their pastor. While the decision is entirely in the parents' hands, women who choose to terminate a pregnancy due to receiving a life-limiting diagnosis are most vulnerable to prolonged grief and guilt. Also, parents should be informed of the availability of palliative care for their infant in the event that their baby with a life-limiting diagnosis is born alive and lingers for a time. Such care allows for the family to meet their baby, process the birth, and together with the medical staff, direct the care of their baby until death.

Pediatric Palliative Care

Infants born with life-limiting conditions require specialized care that involves their entire family. Palliative care, or comfort care, is promoted by the World Health Organization and the American Academy of Pediatrics. Its purpose is to alleviate the suffering of the child while providing the best quality of life possible.

Palliative care is carried out with full participation of the parents. Once a baby has received a diagnosis of imminent death and a "do-not-resuscitate" order has been written (a process that requires review by the hospital ethicist/ethics panel), the focus of care moves to comfort and support. Decision-making is a collaborative process between the parents and medical and social service teams and includes physical, emotional and spiritual support of the infant and family. Some neonatal units have palliative care teams who support the infant and family when there is no possibility of cure or long-term survival. Other units rely on policies and training of staff to prepare them to help families through this tragic period in their lives.

One goal of treatment is that the parents and family create positive memories of their baby's short life. Also, the palliative care process does not end with the death of the child, but seeks to provide on-going support of families as they move through the grieving process. The pastor might be invited by the family to participate on the collaborative care team in the hospital. Occasionally, infants are discharged to die at home with hospice care. In these situations, pastors provide vital care and support of the family throughout the short life of the child.

Naming the Child

If asked, the pastor should encourage the parents to name their child. While we do not have or need a formal naming service for the unborn child, and while the child may not be a baptized member of the community, naming the child will assist in the grieving process. Naming the child allows the parents to grieve the death of the child by name, rather than as an "it." This unborn child is a member of the family, and referring to the child with a name reflects this reality.

Paying attention to Dads

While the mother has a unique and intimate relationship with the child during pregnancy and is likely to experience more intense grief than the father, it is important to check in with the father and be available to provide him with support and guidance. He might be experiencing pain and sadness over the death of the child and all the corresponding losses of hopes and dreams. A father might experience no grief, or might not be entirely aware of his level of grief, and might feel guilty or ashamed of this. He might be struggling as he witnesses his wife going through her physical and emotional struggles. It is easy for a man to feel a sense of helplessness, unable to "do anything" to help his wife with her pain and suffering. A husband can be tempted to distance himself, or suggest coping strategies to his grieving wife that he, himself, has found helpful, but these inevitably will be unhelpful and create tension in the marriage. He must learn how to stay close and be a peaceful, prayerful, listening presence for his wife, while he goes through his own grieving process. The more a husband accepts the notion that his wife's grief is not a problem to solve, the closer the husband can draw to his wife as she mourns. Pastors can

provide information about the grief process and guide the husband to stay close to his wife.

Men tend to grieve differently than women and are less likely to seek out assistance and emotional support. More importantly, each father has his own unique grief experience and mourning process. Typically, the wife is his primary, and often sole, source of comfort and she is likely to be emotionally and physically unavailable to him. Because most of the care and attention naturally will be directed toward his wife, it is easy for a man to be left unattended and alone during this process. In addition to the loss of his child, if he is uncertain, or unable, to draw close to her, he may suffer the loss of emotional and physical closeness to his wife. He might grow weary of the burden of emotional care for his grieving spouse and feel guilt or shame around his own unmet needs and desires.

Paying Attention to the Marriage

While the death of a child can strain a marriage, it can also draw a couple together, with proper communication and understanding. Husbands should be guided and supported to stay close to their wives through this process. They should be encouraged to share their grief, as well as listen to their wives' experiences. Grieving the death of a child can exacerbate some of the normal struggles and tensions in a marriage and can be complicated by unresolved marital issues. The death of a child can serve as an opportunity to attend to these other issues and challenges in the marriage. Depending on the number and intensity of the marital issues, referral to a marriage counselor might be appropriate. A capable therapist can assist the couple in grieving their loss as well as attending to each other and the marriage. Open communication and respect for each person's grief and mourning process will allow the couple to strengthen their intimacy and connection as well as their faith in God's healing presence.

Attending to Siblings

Depending upon their ages and developmental stages, siblings may or may not understand that their mother was pregnant and has lost a baby. Children will certainly be aware that something is wrong and that their mother is sad. Children grieve in unique ways and at their own pace. It is important for children to be told what has happened at a level that they can understand. They may need to have the explanation repeated. They tend to do best when normal family and household routines remain in place, communicating a sense of security and safety. They will also need reassurance that, although their parents are sad, they will be all right. Children need to know that they are not the cause of the baby's death. Older children may be more aware of death, but younger children may be confused and tend to internalize the loss as something they are responsible for. Parents should be encouraged to talk simply but openly about the loss, to answer their children's questions, and to involve siblings in any memorial or burial. For example, families can choose to have siblings lay roses or flower petals over the coffin before the earth is shoveled over it. Children may want to write a note or draw a picture

to be buried with their little brother or sister. Some parishes have a memory garden that can be tended by those who have lost babies. Children can help their parents tend the garden or plant flowers in memory of their lost sibling.

Parish-wide Pastoral Care

While many families will not share their loss publically, others will receive solace in the comfort and care of their spiritual community. Parishes can develop a caring ministry to offer on-going support of these families as they move through the grieving process. Below are some possible parish-wide ministry options.

Liturgical Remembrance Opportunities

One of the most heartfelt fears of parents who have lost infants is that their children will be forgotten. Here are a few examples of ways in which some Orthodox parishes remember departed infants during the liturgical year – be sure to consult with your bishop:

- A Homily on the Feast of the Conception of the Theotokos or the Forerunner
- A dedicated memorial on one of the Lenten Saturdays of Souls
- A special prayer or service on the anniversary of the loss (see "Prayers")
- Annual commemoration during the Great Entrance

Memorial Gardens

Parishes with space on their property can create a special place for memorializing infants lost in pregnancy and infancy, where these infants can continue to be remembered over time. Tending of this site by parents who have suffered losses can be very helpful in assisting them to move positively through the grieving process.

Dedicated Cemetery Space

Those churches that own cemetery land can create an enclosed space for burying infants lost prenatally. These tiny plots should be offered free-of-charge, and maintenance of the area should be entrusted to bereaved parents. Many Orthodox monasteries now have burial ground specifically dedicated for infants.

Health Ministries

Pastors whose parish has a faith community nurse or health ministry team can enlist their help to assist families through the initial phase of the loss experience. It is important to have trained individuals who understand the loss as well as how to support a family in crisis without interfering. Pairing a mother with another woman who has experienced a similar loss may be very helpful in assisting the grieving mother through the process. Studies have shown that women seek the counsel of other women while men tend to

process their loss with their wives. In any case, having an individual who has been asked to maintain an on-going relationship with the mother will be invaluable to the parish priest, since the process of grieving tends to be lengthy and time consuming.

Two Key Points

First: Respect the privacy of the grieving parents.
Many parents will not want to reveal their pregnancy loss to others but will seek solace in the prayers of the Church. Interment of the remains will also be private. Other parents might prefer community involvement in the interment process and find comfort knowing that the community is supporting them through prayer.

Second: This is their experience, not yours.
As with many tragedies, the person seeking to console often seeks to be consoled by talking about their experiences instead of opening themselves up to listen to the parent who has just lost a baby. It is helpful to keep this in mind: serve the parent, not yourself.

What Not to Say

When parents suffer early losses in pregnancy or infancy, well-meaning comments from their families, friends and faith communities can nurture healing in them, or they can cause suffering. A well-intentioned remark that minimizes the loss can be devastating to a mother and father and contribute to years of suffering. Failure of others to recognize and honor the importance of that life to the parents, no matter how small or injured (as in the case of a baby born with lethal anomalies), can turn this loss into trauma and grief into despair. Our calling as the Body of Christ is to walk with our brothers and sisters in their joys and in their sorrows. Helping parents in mourning to feel connected and comforted promotes their healing. So, it is helpful to review some of the comments that are common but most hurtful. Here are some things not to say to grieving parents:

It must have been God's will.
Time will heal.
Comments such as these tend to minimize the loss, and invite the desperate retort, *"If God is a loving God, why did He take my baby?"* There is little solace in pat answers when parents are grieving, so it best to avoid them.

It was just a bunch of tissue.
It was so early, too soon to be a baby.
Why would you name a bunch of tissue?
Referring to the loss in this way trivializes the grief of the parents. While losses in early pregnancy are "invisible" to others, they remain the loss of a child given the breath of life by our Creator.

Well, at least you have other children.
You are young -- you can try again.

Your child is now an angel.
Pat comments such as these tend to devalue the life that has been lost, and are dismissive of the parents' grief.

It's probably for the best.
There was probably something wrong.
What did you do that caused the loss?
Over 50% of all pregnancy losses have no known cause. It is important not to make comments that might lead to blame or guilt in either parent. Parents need reassurance and hope from pastors. These discussions are best left to medical providers.

I guess God wants you to adopt.
Mothers who have experienced recurrent pregnancy losses are often devastated and feel hopeless. Adoption is not the answer to many individual's hopes for a family and should not be touted as such. Leave such advice to professionals.

Move on, dear.
Mothers often remember the anniversary of their loss. It is not morbid nor is it malingering to want to have their baby's "birthday" acknowledged or to want to talk about their baby. One of the biggest fears of parents who have lost children is that they will be forgotten.

Before You Get the First Call

The next sections contain information that every pastor should know before he is ever called to care for someone experiencing a pregnancy loss. Please be sure that you have at least a basic familiarity with your local laws and regulations, as well as the medical language surrounding pregnancy and infant loss prior to responding to a family's call.

Laws and Regulations

In order to be an effective advocate for a mother suffering the loss of an infant during the perinatal period, it is necessary to review the local and state laws and regulations surrounding fetal death, stillbirth and disposition of the remains. Each state specifies the gestational age at which regulations are applied. Individual hospitals have policies and procedures binding their practice and informing their actions regarding the disposition of the remains. Prior to any procedure, (D&C, D&E, labor induction), a physician is required to fully explain the procedure, its risks and expected outcomes. The physician must answer all of the questions asked by the person undergoing the procedure, or by their legal representative. The procedure cannot take place without the consent (i.e. signature) of the mother. When a mother or father requests an action outside of the common policy of the hospital, it is often possible to sign a waiver allowing them to circumvent the practice. An informed pastor can more effectively counsel the couple as

they make decisions about concluding the pregnancy and burying their infant, no matter how small those decisions may seem.

Guidelines for burial are based upon three things: gestational age, weight and whether or not signs of life were noted at the time of birth. Death is simply defined as the absence of any sign of life in the baby, whether born or unborn, regardless of gestation. It is a live birth if a baby is born with one sign of life, (respirations, heartbeat, pulsation of the umbilical cord or movement of voluntary muscles), no matter the gestational age. When an infant is born with signs of life, regardless of gestational age, or weighing more than 350 grams, many states require the family to make burial arrangements with a mortuary.

In most states, when an infant loss occurs prior to 20 weeks gestation, with the weight of the baby below 350 grams (around 14 ounces), and the baby does not show any sign of life, families are not required to bury their baby and may opt for the hospital to dispose of the body. Some hospitals allow parents to sign a waiver allowing them to take the baby home for burial if these criteria are met.

When an infant is born after 20 weeks gestation and weighs more than 350 grams, regardless of signs of life, parents are required to make burial arrangements. Often, hospitals have chaplains who can assist families in making private arrangements, including taking their baby home with them.

It is often necessary to negotiate with funeral directors and cemeteries not owned and operated by a church, in order to fulfill the wishes of the parents and to minimize costs associated with simply burying their loved one. When the law requires formal arrangements for burial, it is helpful to have an established relationship with a funeral director who understands Orthodox burial practices and is flexible in the services they offer. Funeral directors arrange for burial in the cemetery of the parent's choice. They do charge for the services they offer, making it costly for some families.

Cemeteries have differing policies regarding burials. In some traditions, infants are buried over a deceased grandparent. Some churches have cemeteries and have created a special area for those infants lost early in pregnancy, giving their families a dedicated place in which to inter their infant. Cemeteries that allow "green burials" often have the flexibility to allow families to bury their infant in a way that has meaning for them. These funerals typically do not use caskets or burial vaults.

Starting Points

When you are called and asked to help someone who has been given a diagnosis of a perinatal loss, it is helpful for you to have some basic information prior to offering your assistance. Answering these questions will allow you to help the parents sort out their options and make informed decisions during this tragic point in their lives. Some information that is helpful for you to know follows:

- What stage of pregnancy is the mother in?

First trimester (0-3 months) This is the most common time when miscarriages occur.

Second trimester (4-6 months) Babies are fully formed and generally weigh more than 350 grams. Generally an unborn child is considered viable at 24 weeks' gestation.

Third trimester (7-9 months) Babies are gaining weight and preparing for birth.

- Given the stage of pregnancy, what are the laws in your state surrounding infants of this gestation?
- What is the recommendation of the physician regarding the mother's condition? Has the physician recommended termination? Is it necessary? (Is the mother in danger or is it for convenience?)
- Given the gestational age of the infant, what are the likely implications for burial? Generally, losses that occur early, with very small infants, allow for private disposition of the remains. Waivers may be signed by the parents to allow them to take their baby home with them for private interment.
- If the pregnancy is in the second trimester or beyond, do your state laws specify the use of a mortuary for handling the remains? Is it possible for the couple to take their baby home for a private interment? If it is not, is there a funeral director who will allow the couple to bury their infant without all of the accoutrements of a typical funeral (if the family wishes)?
- Where will the infant be buried? What are the regulations of the cemetery? Do they require the services of a professional for opening and closing the grave? Will a vault be required? How far down must the grave be dug for an infant? (Some fathers have found great meaning in digging the grave themselves.) Would it be possible to inter the remains above a grandparent?
- It is important not to over emphasize burial especially when the loss occurs very early in pregnancy. Mothers may not realize they have lost their baby until it is too late to retrieve the body, due to the circumstances of the delivery.
- A word about caring for the body of the infant awaiting burial: it is necessary to keep the body cold until interment. Many families place the tiny remains of their baby in a receptacle and then place it in their freezer until the burial. Funeral directors will care for the remains until burial, also, though there may be a fee for doing so.

Medical Terminology for Pastors

The information in this section is provided for the pastor's own knowledge. It is neither comprehensive nor to be used as a medical reference source. The pastor is never authorized to give medical advice.

A Glossary of Terms and Procedures

Abortion: In medical language, "abortion" means the ending of a pregnancy by death and does not indicate the means. Because the term is applied to spontaneous (occurring naturally) and elective (intentional) terminations, it is often avoided when describing the pregnancy loss of a desired baby. The pastor should exercise great care and sensitivity when using this term.

Blighted Ovum: The gestational sac develops and is able to be seen on ultrasound, but there is no sign of a baby inside the sac. It may be referred to as an "empty sac." This will only occur very early in pregnancy. Sometimes, if an error has been made in estimating the stage of the pregnancy, the baby is not yet visible by ultrasound.

D&C (dilation and curettage, vacuum aspiration): Surgical intervention to remove the baby and placenta from the uterus. It involves both suction and instrumental removal of the contents of the uterus.

D&E/D&X (dilation and evacuation/dilation and extraction): Surgical intervention to remove a baby over 20 weeks gestation in which the body is removed by dismemberment.

Early Pregnancy Loss: a miscarriage that occurs before six weeks.

> *Note:* You may hear the phrase "biochemical pregnancy" used in the context of an early pregnancy loss. Pastoral caregivers should never use this term.

Ectopic Pregnancy (Tubal Pregnancy): The baby has implanted outside of the uterus, usually in one of the fallopian tubes. The fallopian tube is very small and not capable of expanding to accommodate a growing baby. Frequently, ectopic pregnancies are detected in the second month of pregnancy. Acute pain associated with these pregnancies often leads to diagnosis and immediate surgical intervention.

Elective/Induced Abortion: The deliberate ending of a pregnancy. Previously referred to as "therapeutic" abortion.

Expectant Management: Waiting for a miscarriage or stillbirth to complete on its own without intervention. This term also applies to allowing a pregnancy to come to its natural conclusion when the baby has a life-limiting diagnosis.

Extrauterine: Referring to something outside the uterus.

Full Term: A baby born between 38 and 40 weeks in the womb.

Induction: Medically managed stimulation of labor with the intent to proceed to delivery. This process is used to deliver healthy infants as well as those who have died in the womb or are not expected to live outside of the womb once born. A variety of procedures

and medications are used in this process and usually require that the mother be admitted to the hospital.

Intrauterine: Referring to something inside the uterus.

Incomplete Miscarriage (Incomplete Abortion): Partial loss of the baby and placental tissue in a miscarriage. Often, medical intervention is necessary due to bleeding or risk of infection.

Laparoscopy: The surgical procedure most often used to remove an ectopic pregnancy. This results in the loss of a fallopian tube and/or ovary on one side, thus compromising the ability of the mother to conceive in future.

Laparotomy: The surgical procedure often required to remove a ruptured ectopic pregnancy. Involves a larger incision than a laparoscopy and may involve more serious complications.

Life-limiting Diagnosis: The baby is diagnosed with an abnormality or set of abnormalities that would lead to the baby's death *in utero* or shortly after birth.

Missed Abortion: The baby has died (or only a sac is seen) but the actual miscarriage has not yet begun.

Non-viable Pregnancy: Refers to a baby who is too underdeveloped to be able to live outside of the womb. It is occasionally used to describe a pregnancy that is not likely to progress normally.

Palliative Care (Neonatal Hospice): Comfort care provided after birth to the baby with a life-limiting diagnosis. Care is directed by both the parents and the medical team and may occur in the maternity unit in which the other delivers or in a neonatal intensive care unit.

Ruptured Ectopic Pregnancy: An ectopic pregnancy that has ruptured, leading to severe pain and blood loss – considered a medical emergency.

Septic Abortion: A miscarriage that occurs as a result of infection.

Septicemia: A systemic infection in the blood that can become life threatening. Fear of or existence of this condition in a mother experiencing a pregnancy loss will direct the need for medical intervention.

Stillbirth: The delivery of an infant who is born without signs of life, either *in utero* or during the process of birth. Most states consider 20 weeks gestation as the defining criterion.

Threatened Miscarriage: There are signs that a miscarriage may be in progress or may take place, but it is not certain. Some pregnancies progress normally after this diagnosis and some end in miscarriage.

Viability: Ability of the baby to survive outside of the womb. The age of viability recognized by the American Academy of Pediatrics and Association of Obstetricians and Gynecologists is 24 weeks' gestation.

Medical Procedures

A variety of options exists for managing threatened or impending pregnancy loss, including medication, surgery and/or expectant management. Unless a medical emergency is involved, physicians usually offer mothers a range of choices about how to proceed. All but expectant management require informed consent by the mother or her husband (if she is unable to sign for herself).

As described in the above section, medical procedures include surgical intervention, induction of labor and expectant management. Factors to be considered include the stage of pregnancy, whether or not bleeding or infection is present, and the mother's overall condition, both physical and emotional. In many cases, the mother may choose to wait for nature to take its course and for her body to deliver the dead or dying child without medical intervention. A mother who makes this choice requires close monitoring by her medical provider.

Infant Loss at Various Stages of Pregnancy

Early Miscarriage (0-12 weeks)
This is the most common time to miscarry. Associated conditions can include: infection, abnormalities of the uterus, chromosomal anomalies of the baby that are incompatible with life, or immune disorders of the mother. Chromosomal abnormalities are implicated in over 50% of first trimester losses.[i] Determination of fetal age is initially by presence of a heartbeat, typically seen between 6-8 weeks in a normal pregnancy and/or visible body parts, which usually are visible by 8 weeks gestation.

Late Miscarriage (13-20 weeks)
Associated conditions can include: infection, accident, abnormalities of the uterus, congenital abnormalities of the baby that are incompatible with life, umbilical cord accident, premature labor and rupture of membranes, or abnormalities of the placenta. Babies delivered at this stage are recognizable. Occasionally, a baby born around 20 weeks gestation will be born with signs of life and thus is termed a "neonatal death". Resuscitation efforts are usually not performed on any baby under 24 weeks gestation.

Due to the size of the baby, surgical procedures to remove the body carry more risk to the mother and may include dismemberment. The closer to 20 weeks the more likely induction of labor is to be recommended. Though more lengthy, the induction process

offers a gentler way for the baby to be born and thus, avoid the regret often felt by mothers who choose surgical interventions like D&E.

Stillbirth (20 weeks to full term)
Stillbirths (babies lost late in pregnancy) are often associated with maternal disease, (e.g. hypertension, stroke) or accidents, (e.g. placental abruption, cord accidents). Babies are fully recognizable. Usually, labor is induced or occurs naturally. Occasionally, delivery is by cesarean section, however, this is not considered best practice for managing infant loss in late pregnancy in the absence of serious maternal disease. When unexpected, medical providers will attempt a full resuscitation of the infant before declaring the infant deceased, but the baby will be considered stillborn, having been born without signs of life.

Life-Limiting Diagnosis

Depending on the diagnosis, the baby may die *in utero* or may die within moments to weeks or even months after birth. It can be difficult to predict the outcome. Delivery of these infants may be induced or occur naturally. Hospitals that provide maternity services are presumed to be able to offer palliative care to newborns. If not, infants who survive birth and are not expected to die imminently will be transferred to a neonatal intensive care unit where palliative care is available.

Myths and Misinformation

Miscarriage and stillbirth has traditionally been a closed topic – not discussed in the open. Because of this there is an abundance of misinformation among the general public. Because humans are rational beings they tend to search for meaning and cause even when there is not a known cause. This can lead to harmful beliefs and can result in the mother blaming herself for the loss of her baby. Thus, it is very important that the pastor be well versed in factual information when counseling the family or addressing the parish at the time of an infant death.

Some myths about the causes of miscarriage and stillbirth:

- You were feeling ambivalent about the pregnancy – you didn't love the baby enough.
- You ate spicy food.
- You had a glass or two of alcohol.
- You picked up something heavy.
- You had pregnancies that were too close together.
- You are not praying enough.
- The baby was conceived during a fast.
- God is punishing you.

Myths in the Church about pregnancy loss:

- You can't name a baby who died before the naming prayers on the eighth day.
- Unbaptized babies can't go to heaven.
- Unbaptized babies can't be buried in consecrated ground.

Please assure parents that their baby can indeed be named and buried, and that we are confident in entrusting their child to God's care.

Facts about the causes of miscarriage and stillbirth:

- It is nearly impossible for a woman to *cause* a miscarriage.
- It is estimated that up to 1 in 4 pregnancies will end in miscarriage
- Approximately 1 in 4 women will lose at least one pregnancy in their lifetime.
- In the US, the incidence of stillbirth is approximately 1 in 160 births.
- The vast majority of stillbirths are not preventable.
- Miscarriage and stillbirth are more common among very young women and those who are 35 years of age or older.
- Miscarriage and stillbirth are more common in a pregnancy with twins or triplets.
- Chromosomal anomalies are implicated in over 50% of miscarriage in the first trimester. Most often, however, the specific cause of pregnancy loss is unknown.
- Some factors associated with miscarriage and stillbirth include sexually transmitted diseases, a previous history of an abortion, uncontrolled chronic disease (such as diabetes), thyroid disorders, maternal blood clotting disorders, mothers who smoke or abuse drugs, chromosomal anomalies, uterine malformations, placental malformations, and cord malformations. This is *not* a complete list, nor are all of these factors known to actually cause miscarriages or stillbirths.

Pastoral Care and Advocacy – A Summary

Pastors can advocate for the mother, parents and their child in many ways. You can be a healing presence in this time of great stress and grief. You can embody the love of God, the presence of Christ and the ministering presence of the Church as issues are confronted and decisions made. Keep in mind these basic principles of caring for those who have suffered infant loss.

Facing the tragic news that their baby has died, parents are often unable to take in all that is said by their physician. It is important for parents not to rush their decision-making, but rather to ask questions and delay consenting to medical procedures until they have adequate time to review their options, consider the risks involved now and for future pregnancies.

When working with families and their medical providers, it is helpful for pastors to remember the following:

1. Do not give medical advice.

2. Help the mother or parents make decisions about procedures, help them navigate the technical and legal issues, and help them bury their child.

3. Be present for the mother and family. You also can offer to be present when the mother meets with medical personnel, to help her understand what she is being told, and to help her communicate her wishes clearly.

4. Listen. Help the mother or parents make sure they understand all the available options. Help the mother or parents sort out the options, come to terms with their own priorities and desires, and make an informed decision without pressure or hurry. Bring a sense of calm and a feeling of safety to the situation, and give parents time to think.

5. Parents who chose expectant management will need support and sensitive care throughout the remainder of the pregnancy and the grieving process. Siblings and grandparents may also be in need of assistance.

Resource Materials on Infant and Pregnancy Loss

Orthodox Resources

Websites

Lost Innocents http://lostinnocentsorthodox.blogspot.com/ Practical help for miscarriage and stillbirth from an Orthodox perspective

Naming the Child – http://namingthechild.com/ The web companion to the book, *Naming the Child,* by Mat. Jenny Schroedel

https://pruncipierdutisinascutiinaintedevreme.wordpress.com/ The Romanian counterpart to *Lost Innocents*, written by Preoteasa Eufemia, a preoteasa (priest's wife) in Romania.

Books

Naming the Child, Hope-Filled Reflections on Miscarriage, Stillbirth and Infant Death, by Mat. Jenny Schroedel.

Non-Orthodox Resources

Websites

Babies Remembered - http://wintergreenpress.org very comprehensive site with extensive book list, collection of resources, news articles, pertinent legislation updates, medical studies, etc. Plus, the author is an international speaker to hospital groups and others on the subject of infant loss and bereavement.

Life and Loss https://lifeandloss.wordpress.com A blog/site by a perinatal hospice nurse who has herself suffered loss. Excellent information for everyone but especially for those in the health care arena. Focuses on perinatal hospice.

Angel Babies http://angelbabiesinfo.com/ "practical information for parents coping with late pregnancy and infant loss"

Coping Together http://copingtogether.info Comprehensive resource for both men and women who are struggling with the loss of a baby through miscarriage. While there is much information to be found for the woman who grieves, little exists for the grieving man, or the impact this loss has on the couple's relationship."

Pregnancy Loss http://americanpregnancy.org/pregnancy-loss "At this site you will find information and a place to come in your dark and frightened hours. The special features of the site are listed in the next column, as well as topics ranging from causes of miscarriage, to prevention, to when to try again for a new pregnancy."

Faces of Loss http://facesofloss.com/ A site devoted primarily to the sharing of stories of pregnancy and neonatal loss.

Non-Orthodox Books

A Silent Sorrow, by Ingrid Kohn, MSW and Perry-Lynn Moffitt. Pregnancy Loss: Guidance and Support for you and your family

Unspeakable Losses, by Kim Kluger-Bell. Healing from miscarriage, abortion and other pregnancy loss

Dear Cheyenne, by Joanne Cacciatore. A heartbreaking, hope filled collection of letters and poetry that Joanne wrote for her daughter, Cheyenne, who died during labor.

Empty Cradle, Broken Heart: Surviving the Death of Your Baby, by Deborah Davis

A Grief Observed, by C.S. Lewis

A Broken Heart Still Beats: After Your Child Dies by Anne McCracken and Mary Semel

Trying Again, by Ann Douglas & John R. Sussman, M.D.

A Silent Sorrow, by Ingred Kohn & Perry-Lyn Moffitt

Thinking About Another Pregnancy, from the Miscarriage Association

Other Resources

American Academy of Pediatrics, Section on Hospice and Palliative Medicine- articles and guidelines for pediatric and neonatal palliative care with links to information for health professionals and parents.

Now I Lay Me Down To Sleep – Infant Bereavement Photography. All services are offered free of charge.

NICU Helping Hands – burial clothing for miscarriages, Micro Preemie through 40 week gestation. angelgowns@nicuhelpinghands.org

Perinatal Hospice and Palliative Care -- information on decision making for parents as well as extensive provision of resources for parents and professionals http://perinatalhospice.org

PRAYERS

Jurisdictional practices regarding services vary widely. There is yet no common service approved for use by Orthodox Church in cases of perinatal loss. Pastors should consult with their Bishops for guidance.

Prayer for a Woman Bearing a Child Who Has Died in the Womb

O Lord God Almighty, the Creator of all things and the Lover of mankind: we beseech Thee to bless this Thy handmaiden, **[N],** who is bearing the child that has died in her womb. Grant her help and comfort at this trying time; ease her labor, and keep her safe through delivery. Yea, O Lord, open the treasury of Thy mercies and compassion unto her. For Thou art the Physician of our souls and bodies, O Christ our God, and unto Thee do we ascribe glory, together with Thine unoriginate Father and Thine all-holy, good and life-creating Spirit, now and ever, and unto ages of ages. Amen.

Prayer for a Family in Grief following a Miscarriage

O Lord our God, who spoke through the prophet Isaiah saying, "Behold I create new heavens and a new earth; and the former things shall not be remembered or come to mind…no more shall be heard the sound of weeping and the cry of distress. No more shall there be in it an infant that lives but a few days..." (*Is 65:17-20*) Do Thou, the same Lord, draw near and comfort all of your servants who mourn the loss of this child, (Name), known to the mother who carried him/her, to the father who generated him/her, to the grandparents (siblings) who anticipated him/her. For Thou art our Consolation, O Christ our God, and unto Thee we ascribe glory, together with Thine unoriginate Father and Thine All-Holy Spirit, now and ever and unto the ages of ages. Amen.

Prayer for Healthcare Providers

O Lord Jesus Christ our God, Lover of Mankind, Physician of our souls and bodies, who didst bear the pain of our infirmities, and by whose wounds we are healed; through your physicians You grant healing and relief from pain (*Sirach 38:8*), do Thou now, O Lord, grant Thy grace to the physicians, nurses, and attendants through whom You care for your handmaid (N.), who is suffering. Strengthen them, by Thy strength, to fear no evil or disease, and grant them peace. For Thou art our God, and we know no other, and to Thee we ascribe glory together with Thy Father who is from everlasting, and Thy most Holy, good, and life-creating Spirit, now and ever and unto ages of ages. Amen.

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[i] First Trimester Miscarriage Evaluation, R. Lathi, F.Hazard, A. Heerema-McKenney, J. Taylor, and J. CheueH, Seminars in Reproductive Medicine, 2011; 29 (6): 463-469.