

UNDERSTANDING YOUR PREGNANCY LOSS

Coping with Miscarriage, Stillbirth or Newborn Death

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The Pregnancy Loss Support Program is a community service of the National Council of Jewish Women New York.

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YOUR EMOTIONS

Grief is a normal and necessary reaction to miscarriage, stillbirth or newborn death, and it lasts far longer than most people realize. Grieving parents may experience a variety of emotions following a pregnancy loss, including shock, anger and helplessness. Gestational parents and their partners often express their grief differently, so try to be patient with yourself and your partner during this difficult time.

Nearly one third of all conceptions end in some type of natural pregnancy loss. About 80 percent of these occur in the first three months of pregnancy, around 14 percent in the second trimester and approximately six percent in the third. But statistics mean very little when you have lost your baby. "No matter what the chances are," said one grieving parent, "if it happens to you, it happens 100 percent."

Since some causes of pregnancy loss can be determined, such as structural, genetic, or hormonal problems, it is important to discuss your individual experience with your healthcare practitioner. This will enable you to decide on procedures and tests which may help you understand the loss and plan for a future pregnancy.

Whether you suffered a first trimester miscarriage or a full-term loss, many of the grief issues are the same, but other concerns will vary depending upon how far along you were in your pregnancy. Most grieving parents feel intense emotional pain and a sense of emptiness following any pregnancy loss. Your immediate feelings of shock and numbness may be followed by crying jags, poor appetite, too little or too much sleep, anxiety, lack of self-care and depression. Bereaved parents may have trouble getting through your daily tasks at home or at work and may experience your feelings as being completely out of control. Many parents feel intensely cheated and wonder "why me?" They sometimes feel angry at the medical staff involved in their care, or at God, their friends, or even family members who don't seem to understand their grief. Anger needs to be shared in a healthy and acceptable manner so it can be confronted and resolved. This is all part of grieving your loss.

The ability to bear the intense feelings of grief following a pregnancy loss varies from person to person. Many individuals find validation, understanding and comfort by participating in a support group with other grieving parents. Knowing that you are not alone in your experience or feelings is an important first step in beginning a healthy grieving process. If either parent suffers from a persistent grief response that does not seem to improve after a few months have passed, sessions with a professional trained in pregnancy loss bereavement can be helpful.

The Gestating Parent's Response

Often the partner who carried the pregnancy expresses their grief openly with friends, family and healthcare providers. Their sense of loss may be more acute than your partner's and you may need more time to mourn. Expressing your emotions in a supportive environment will enable you to understand and eventually accept your feelings of grief. Some gestating parents feel a sense of failure, as if their bodies hadn't protected and nurtured their babies properly.

Others may feel guilty, which can surface in "if only" thoughts, such as, "If only I had stopped working sooner," or "If only I hadn't continued jogging." Keep in mind that physical activity rarely, if ever, causes pregnancy loss and that finding someone or something to blame is a normal way of trying to explain the inexplicable. Some who have lost a pregnancy may have unusual sensations, such as imagining that they hear a baby's cry, or feel aching arms, or kicks from inside the womb. These feelings are a part of normal grief.

No matter when your loss occurred, your body will be struggling to cope with a dramatic change in hormone levels. Crying uncontrollably and feeling "blue" are typical hormonal and emotional reactions. Most gestating parents who suffer early miscarriages may suddenly feel the end of pregnancy symptoms, such as tender breasts or morning sickness. Following any pregnancy loss, most will experience a vaginal discharge called lochia, which will gradually decrease and change in color from red to pink and eventually will become white. Sanitary pads should be used during this time. Tampons and douching are not recommended. You may shower but speak with your health care practitioner before taking a bath or going swimming. Mothers who carried their babies beyond the first trimester sometimes have to cope with their breasts filling with milk. You can talk to your healthcare practitioner about medical options, but many women find that wearing a supportive bra 24 hours a day until their breasts begin to soften usually helps. Cold compresses such as gel packs, ice packs or raw, rinsed, cold green cabbage leaves applied directly to your breasts can make you more comfortable. In most instances, breast fullness will go away within a week.

Heavy lifting, strenuous physical work and vigorous exercise should be avoided after any pregnancy loss until you are advised by your healthcare practitioner that it is safe to resume these activities. Be prepared that the follow-up visit to your practitioner can be filled with emotion. Returning to the place that had once held so much hope and anticipation is not easy. Since it may be difficult to see other pregnant women and babies in the waiting room, ask for the first appointment of the day, or to be ushered into an examining room immediately upon your arrival. Keep in mind that the follow-up visit can provide an important opportunity to ask some of the many questions which you may have about your loss. Again, individual or peer support counseling can be helpful, so be sure to speak with your healthcare practitioner for referrals or contact the PREGNANCY LOSS SUPPORT PROGRAM.

A Partner's Response

So much attention is paid to the parent that was pregnant that bereaved partners' feelings are often ignored or misunderstood. Their grief for the baby may be mixed with tremendous gratitude for their partner's health. They often feel helpless, guilty and angry over the pregnancy loss, as if they have failed to fulfill the role of protector and provider. Male partners, especially, may be less expressive about their feelings in an attempt to be "strong" for their family during this stressful time. Because of this, you might be concerned that showing your own grief will make the baby's parent who was pregnant feel worse, although this is rarely the case. In fact, attempts to protect your partner by not discussing your grief could cause them to

misinterpret your own feelings and behavior, and begin to question how much you cared about or wanted the baby.

Be sure to reach out to others and discuss your pain, if you feel the need. Here, too, pregnancy loss support groups can be helpful in putting you in touch with other partners who are struggling with the impact of a pregnancy loss. Realizing that you are not alone in your feelings can be very comforting.

Couples Grieving Together

The different rates and intensities of mourning between grieving parents are called "incongruent grief." Once couples understand incongruent grief, they can become more patient with each other's variations in expressing sadness. It can help to talk about your grief responses and try to accept each other's feelings. The couple that continues to communicate during bereavement will grow closer together, rather than be driven apart by the differences in their grief experiences.

The impact of a pregnancy loss may affect many other aspects of your relationship, such as when to resume having sex, what method of birth control you choose and when to conceive again. Keeping the lines of communication open is extremely helpful. Whenever possible, try to put off major decisions, such as moving or changing jobs, immediately after your pregnancy loss. Many couples find that the resolution of grief is best achieved under stable life circumstances. Change, in and of itself, does not heal feelings of loss.

People sometimes turn to substances in times of hardship. Drugs, alcohol and medication can dull emotional awareness and even delay the grieving process. If you find yourself turning to substances, reach out to a healthcare provider for support.

HONORING YOUR BABY

No matter when their loss occurred, most families begin to feel a sense of acceptance when they are able to honor the place their baby has in their lives by creating memories or performing a comforting ritual. Some ways of remembering your baby may be more appropriate depending on when you experienced your pregnancy loss, but you should consider any source of comfort if it feels right for you.

Some parents remember their babies by:

- Planting a memory garden, which you can add to each year. Add a baby or angel statue
 to watch over the garden. Some choose plants that are symbolic of remembering such
 as rosemary or that are symbolic of babies such as baby's breath or tiny flowers such
 as Cecile Brunner roses.
- Donating money to a charity that does research into pregnancy loss or helps bereaved parents.

- Creating a collage of memories that are tangible—photos of when you were pregnant, pressed flowers from flowers you received, cards, leaves from the memory garden or ultrasound pictures.
- Making a donation each year of a book for a school library.
- Naming a star for your baby at <u>StarRegistry.com</u>
- Buying a piece of jewelry like a locket and inscribing the baby's name or starting a charm bracelet to which you can add symbolic charms at each significant date.
- Creating a quilt that has a pattern or images that symbolize your baby to you.
- Lighting a memorial candle on the due date or other significant dates.
- Sponsoring the flowers at a religious ceremony at your local church or synagogue on a date that is connected to your loss.
- Honoring your baby annually at a Memorial Program.

Seeing Your Baby

Parents find that seeing, holding and touching their baby can be very comforting. Many parents who were not given the choice to be with their baby wish that they had experienced this chance for closeness and saying goodbye. It may be the only time you will be together as a family. If you are not sure what your baby will look like, ask your healthcare practitioner to describe the baby's appearance first. If you have already seen your baby and want to see your infant again, this can usually be arranged by the hospital or birthing center staff.

Naming Your Baby

Choosing a name for your baby is one of the most powerful rituals you can perform. A special name gives your baby a strong identity and a firm place in your memories. No matter how far along you were in your pregnancy, you may name your baby, either informally, or with a ceremony, which can be as traditional or unique as you wish. Well trained healthcare practitioners, hospital chaplains, members of the clergy and bereavement counselors can guide you and provide a naming certificate for your baby. If you don't know the baby's gender or don't have a strong sense of the gender, choose a gender-neutral name. Giving a baby a name can help when the loss feels invisible.

If you missed this opportunity, you may still find comfort and validation by naming your baby whenever you feel ready. Framing a completed naming certificate or placing it in your baby's memory box can provide a tangible reminder of your child's presence in your life. You may find naming certificates on the Internet or through bereavement catalogs.

Taking Photographs of Your Baby

Most hospitals and birthing centers will offer to take photos of your baby for you to keep at home or in their files until you are ready to see them. Some parents choose not to look at their photographs right away, but find they later become treasured keepsakes.

Keeping Mementos of Your Baby

Couples who suffer an early pregnancy loss often find saving sonogram pictures or positive pregnancy test results can help make a brief pregnancy real. Even photographs of the mother while she was pregnant can provide a special remembrance of your baby's presence in your lives. Parents who experience later losses have more choices concerning keepsakes. If your baby was wrapped in a blanket, or was wearing clothing or a cap, you may want to save these items, along with a lock of your baby's hair, footprints or hospital identification bands. If you are unsure about taking mementos home, ask your healthcare staff to keep them on file for you so that you can take your time deciding what is right for you.

Finding a Place in Your Heart

While the memory of your pregnancy loss will remain forever, the pain of your grief will eventually lessen. You need to grieve in your own time and in your own way. Once you have integrated your sorrow and your memories into your life, you can find healing and hope for the future.

FINDING COMFORT

Many families find solace in their religion following a pregnancy loss. Consolation may involve an informal prayer session with a hospital chaplain at your bedside or the creation of a ceremony for your baby in the hospital chapel, your own house of worship, a funeral home, or your family's home.

Jewish Traditions

Jewish practices vary among Orthodox, Conservative and Reform congregations, so if you are observant, it is best to speak with your rabbi. No matter what your affiliation might be, your baby may be buried with the support of a funeral director or through the Jewish Burial Society. In Orthodox Jewish tradition, there is no prescribed ritual if your loss occurred early in your pregnancy, but when a baby takes on human form, the baby is named and buried without a formal ceremony or shiva. A ceremonial circumcision is performed for a male baby. If the child lived for at least 30 days following birth, burial rituals are the same as for an adult and shiva is observed. An autopsy may not be performed unless it would directly benefit a future pregnancy or the life of another person. According to Conservative and Reform Jewish practice, rituals may include a formal burial, naming the baby and holding a memorial service. An autopsy may or may not be permitted, so it is best to consult your rabbi or a hospital chaplain.

Christian Traditions

Many different types of formal and informal rituals are encouraged in the Christian church, including cremation, burial, church services, hospital chapel observances and private memorial ceremonies. Naming is always appropriate following any form of pregnancy loss. The major concern revolves around baptism, which is considered a sacrament for the living and is generally not administered to babies after death. There are exceptions, so you should check with your own clergy member or a hospital chaplain. In an emergency, anyone may baptize a living baby either in the womb or at birth, and offer comforting blessings involving water, prayer and scripture. Decisions particular to Catholicism include holding a wake and celebrating a requiem mass for the baby. Hospital chaplains can advise you, but you should also check with your parish priest or pastor.

Islamic Traditions

Muslims believe that the soul is breathed into a baby 120 days after conception. According to Islamic traditions, a child who dies is a credit to her mother and father in the hereafter. Miscarriages before 9 weeks of pregnancy do not require a ritual; however, if the loss is after 16 weeks gestation, your baby can receive the same rituals as an adult who dies, including being named, ritually washed, and clothed. For further guidance, you may contact an Islamic Center or your imam.

Creating Your Own Traditions

Many parents from interfaith families or those without strong religious traditions are comfortable creating a pregnancy loss ritual based on their individual beliefs. If you wish to design your own ceremony, speak to a spiritual advisor of your choosing and incorporate significant elements from your lives, such as music, poetry, flowers, or candles, into your own personal and meaningful observance.

GOING HOME

Leaving the hospital or birthing center with empty arms following a pregnancy loss is difficult. Your family and friends may want to be helpful but might not know what to say or do. You may have other children who are wondering why you are grieving or who worry that their own ambivalence about welcoming an infant sibling might have harmed the baby.

Helping Your Other Children Cope with the Loss

Parents often want to protect their children from the sadness of a pregnancy loss or newborn death. Since children are sensitive to their parents' moods and will wonder why they are so sad, avoiding discussion often makes children more, not less, upset. A simple, honest, and consistent explanation that reassures children of their own safety is most helpful. The concept of heaven is not something children can easily grasp so it is not recommended to rely on "heaven" as being the answer to where your baby is. It is important to explain that no one in the family caused the death by wishes, thoughts or actions, since normal feelings of sibling

rivalry may make a child feel responsible. Do not describe death as "like being asleep," since this could result in a child's having difficulty at bedtime. The baby's cause of death should be explained as different from the sicknesses that healthy people usually contract, so children will not panic when they or family members become ill.

The way children express their feelings about a loss will vary, depending on their ages. Young children may think the loss is temporary and will need gentle reminders that the baby will not be coming home. They will ask questions many times and will need to hear your answers repeatedly, even months after the loss. If you are patient and answer simply, their concerns will gradually subside. Children should be given the option to participate in any rituals but should not be forced to take part if they choose not to.

Coping with the Reactions of Your Family and Friends

Family and friends may not know how to comfort you. Some might choose not to talk about the loss because they believe it might upset you. You may have to start conversations about your pregnancy loss to let others know that talking about it is important to you. Suggest ways in which loved ones can be helpful, from bringing you dinner, to sitting with you while you go through the baby's nursery. Well-meaning people often make comments that are meant to be comforting, but are, in fact, hurtful because they discount the grief you feel. You might hear such remarks as "It happened for the best" or "You can have another baby," neither of which validates your sorrow. You may prefer to state simply that you wanted this baby and are very sad about your loss.

Dealing with the Baby's Clothes, Toys and Gifts

Many parents have found it therapeutic to put the baby's clothes and toys away themselves when they feel ready. You might choose to keep some gifts for future children, return others, donate some to charity, or save a few items in a special memory box to honor the baby who never came home. For those parents who have already prepared a nursery, it is best to delay any decisions until both parents can help decide. There is no right or wrong way to handle these choices. You must do what works best for you, whether it's having others put away the baby's layette or handling this yourselves. You should not allow others to push or rush you.

Being Aware of Unwanted Solicitations

It is possible that unwanted and inappropriate advertisements or solicitations about babies may come to you after your loss by e-mail, regular mail, or by phone. Since this can be painful, try to have a response prepared that will discourage future contact. You might want to write or call the sources of any contacts and ask that you be removed from their lists.

Returning to Your Usual Activities

Parents often find it difficult to return to work or their normal routines following a pregnancy loss. Your level of concentration could be erratic, your moods can change easily and you may be emotionally sensitive. It is best not to attempt to return to work or other activities until you feel

physically and emotionally ready. Explore with your employer if you are entitled to leave time, and use that time if it is available. If you are planning to return to work, try to begin with a limited schedule in order to avoid feeling overwhelmed.

Once you return to your usual routine, you may encounter upsetting situations, such as unintentionally hurtful comments from people. Some might ask questions you find too intrusive, while others may not even mention your loss. If you've experienced a full-term pregnancy loss, you may meet people at work or on the street who will ask about the baby. By considering how you might respond to these situations beforehand, you may find them less upsetting when they do occur. For example, you could plan to say, "I have sad news. Our baby died, but I really appreciate your asking about us."

Being with pregnant people, babies or young children can engender jealousy towards both strangers and loved ones. You may experience mixed feelings about pregnant and parenting family members and friends following your loss. While wishing them well, you might also feel angry because they have what you don't. Protect yourself by giving yourself permission to avoid contact with relatives and friends who are pregnant, or who have young children, until you feel ready. It is important to take care of your needs.

Anticipating Anniversaries and Other Difficult Times

The first year following a pregnancy loss is usually the most difficult, but feelings of sadness often last much longer. Significant moments, such as the arrival of your due date or the anniversary of the baby's birth and death, can cause a recurrence of sadness called "shadow grief." Holidays such as Christmas, Chanukah, Mother's Day and Father's Day may be more stressful than you anticipate. Try to arrange additional support for yourself as these difficult times approach. You may even want to plan something special for yourself and your family in order to acknowledge the loss. This may make it easier to get through the difficult times.

SAYING GOODBYE

Many grieving parents have never considered the issue of a final resting place for themselves, let alone their children. Thinking about what you want for your baby can be very difficult. Knowing what to expect can help you make decisions that are best for you and your family. Even with miscarriage, where burial is not common, parents can request their baby's remains for a private service. Since rituals and burial observances vary with religious practices, you might also wish to consult the clergy affiliated with your own congregation. The gestating parent should always be included in decisions and preparations for a goodbye ritual, even though she may still be in the hospital. If the parent who carried the pregnancy cannot attend a specific ritual, a memorial service which includes her may be arranged for a later date.

You Are Your Baby's Closest Relative

If your baby was born in a hospital or birthing center, knowledgeable healthcare providers and bereavement counselors can help guide you through these difficult choices, including signing

any necessary consent forms. No matter what your circumstances are, you are your baby's and your family's best advocate. If you need time to make a decision, or to be with your baby before you make a choice, be firm about your wishes.

Choosing Fetal Examination or Autopsy

Examination of fetal tissue following a miscarriage or an autopsy on a late term baby may provide helpful information about your loss. Both procedures are optional and sometimes require parental consent. Reports are generally completed within three months and are sent directly to your health care practitioner, who should be alerted if you want to discuss the results as soon as they are available.

Receiving Birth and Death Certificates

The hospital social worker should be able to give you information about local laws regarding birth and death certificates which vary widely by state. New York State law requires that whenever there is a live birth followed by a death, both a birth and a death certificate are completed. If you do not receive the birth or death certificate in the mail, you may request copies from your local Department of Health. In New York City, certificates are available from the Department of Records and Information Services. The best way to access information about applying for copies is to visit their website at https://www1.nyc.gov/site/records/index.page or their office at 31 Chambers Street, Room 103, NY, NY 10007. Several states have passed laws requiring officials to issue both birth and death certificates for stillborn babies.

Private Burial or Cremation: You may contact a private funeral parlor to make arrangements for your baby. The funeral director can assist you in purchasing a grave site or can arrange for your baby to be cremated or buried in an existing family plot. As fees vary, most families contact more than one funeral director. If there are no religious constraints, some families choose cremation because it offers flexibility about scattering ashes, or reserving some for burial later.

Hospital Cremation: Most hospitals can provide a medical cremation at your request. You will not be able to receive the ashes or be present at the cremation, so be sure to research this option carefully. This option may be available only up to a specific gestational age.

Financial Assistance: Although some arrangements are free, burial and cremation fees can range widely, so ask questions directly, or have a family member or close friend handle this for you. Life insurance policies or trade unions may cover some funeral costs, so be sure to check on any coverage you might have. Public Assistance recipients and others experiencing financial hardship should ask a knowledgeable social worker about limited help with these expenses.

Five Things You Need to Know: Funeral and Burial Information in New York*

1. There are several burial options for families.

These include the use of an existing family plot or the purchase of a new plot. Some cemeteries, such as Pinelawn Cemetery on Long Island, have special sections for babies and a baby of any gestational age (even after a first trimester miscarriage) can be buried there.

2. Burial and cremation costs vary greatly.

Some funeral homes do not charge families who have experienced a perinatal loss, or the loss of a newborn. Others may offer a discounted fee, although fees vary widely. Cremations are done at a lower cost than a burial. Parents can decide whether or not to keep the ashes.

3. If you would like a funeral or cremation for your baby the first thing to do is to call a licensed funeral home.

The funeral home will help facilitate burial or cremation.

4. If you experience a loss in New York City before 24 weeks gestation or on Long Island before 20 weeks gestation, and you want to pursue burial or cremation as a family, you must request the remains.

In the absence of a specific request most hospitals will take care of the remains for you, either with the hospital waste or in NYC by burial in a communal grave for infants at Potter's Field.

In New York City, there is a free burial available which takes place on Hart Island in Long Island Sound. Babies are buried in common, unmarked graves and it is not customary to visit this cemetery at internment or afterwards. Please check with your local municipality for more information on any restrictions.

5. You may request death certificates.

Bereaved mothers can request fetal death certificates from the Department of Health and Mental Hygiene for a death that occurred within New York City. For deaths outside of New York City, mothers can request a fetal death certificate from the NYS Department of Health.

*This listing was prepared in consultation with Plaza Jewish Community Chapel which offers free funerals to parents who have experienced a perinatal loss in NYC.

TERMINATION FOR MEDICAL REASONS

Some parents are faced with devastating realities about the viability or health of their baby and/or the gestating parent's own health because of the pregnancy. Many factors are involved in the decision to terminate a pregnancy for medical reasons. Parents often endure days or weeks of uncertainty, follow-up tests and second opinions on this journey. Parents who terminate a pregnancy are especially likely to experience feelings of guilt and need space to process their experience through professional or peer support.

PLANNING ANOTHER PREGNANCY AND PREGNANCY AFTER LOSS

Give yourself sufficient time to mourn and to recover your physical and emotional strength before you consider having another baby. A pregnancy following your loss may be more emotional and anxiety-producing than any previous pregnancy. Give the baby you lost a special place in your heart and think of the next pregnancy as a new baby. Each child is unique and can never be replaced.

Visit https://pregnancyafterlosssupport.org/ to learn more.

FINDING SUPPORT

Well-prepared healthcare providers will offer support to grieving families through their hospital or birthing center perinatal bereavement teams, which usually consist of social work and chaplaincy staff, as well as nurses, midwives and doctors involved directly in your care. They can help you make decisions about mementos, autopsies, and tests, and can refer you to other resources, such as a pregnancy loss support group. Your obstetrician should also have available information about local bereavement support services.

Joining a support group with other parents who have experienced pregnancy losses can be a great source of comfort. Professional counseling or psychotherapy may help individuals, couples or families during the stressful period following a pregnancy loss. Compassionate family members, friends or clergy can also provide validation and solace. Parents need and deserve support during their bereavement. Feelings that are expressed and shared gradually become more bearable.

Pregnancy loss support groups generally fall into one of two formats: drop-in groups, which meet periodically and accept any bereaved parents at any stage of grief; or closed groups, which ask bereaved parents to sign up for a set number of sessions with the same group of parents over several weeks. Both drop-in and closed format groups may be run by a social worker, nurse, or bereavement counselor, or by professionally trained volunteers.

The Pregnancy Loss Support Program offers nation-wide services, including telephone counseling and support groups, for women and men who have suffered a miscarriage, stillbirth

or newborn death. Support groups meet once a week for six consecutive weeks. Groups are facilitated by professionally trained and supervised volunteers who have experienced a pregnancy loss and have participated in a Pregnancy Loss Support Program group. Counseling for a subsequent pregnancy after a loss is also provided. Programs are non-sectarian and free of charge, although donations are suggested and welcomed.