

# Understanding your perinatal loss



# Dear Family Members,

Please accept our deepest sympathy for the loss of your baby. It is difficult for anyone to fully comprehend the pain you and your family are experiencing.

We prepared this booklet to answer questions you may have during this experience. Some of the materials may not be easy for you to read right away. We understand and hope that as time goes by, you can use this resource to help ease the burden of this difficult experience.

We know that while this booklet may be helpful, it is not a substitute for the human touch. The comfort of friends, relatives, staff and various communities who have faced loss can be immensely helpful. We realize it is extremely hard to make important decisions about the final care of your baby at this most difficult time. It is our sincere hope that the following information will help you make those decisions.

Some of the words and ideas in this booklet may seem impersonal. We do not intend it to be that way – we have found that this is the most effective way to present this information. Our thoughts and condolences are with you at this difficult time.  
Sincerely and with sympathy,

The Inova Team

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# Choices before delivery

There are many decisions to think through prior to the delivery of your baby. Please tell your nurse if you would like to:

- Name your baby
- See your baby
- Hold your baby
- Bring your own outfit from home or use our handmade gowns and blankets
- Memory making, hand and footprints, molds, and other important memories or mementos you wish to create
- Utilize the CuddleCot or Caring Cradle \*explained in the section below
- Engage in a religious ritual like Baptism, Name Dedication, Tahneek etc.
- Take pictures of or with your baby
- Bathing baby
- Consider time with yourself/siblings and your baby before considering visitors during your stay

# Funeral arrangements and considerations

## Choosing a funeral home

If you have decided to have a burial or cremation, you must first select a funeral home to handle the arrangements. The funeral director will discuss the services provided and the types of funerals and burials available.

Funeral homes are required by law to tell you exactly what they are charging for each service before they provide it. They are also required to provide their fees over the telephone. The final cost will depend on the funeral home, the type of funeral and services, and the cemetery you choose. Many funeral homes will make alternate financing arrangements or give special rates for their services.

If managing these details feels too painful or overwhelming, a trusted family member or friend may be able to help.

If you have not chosen a funeral home before discharge, you may have been given a list of local funeral homes, once you have chosen one, please contact Inova **Office of Decedent Affairs** where you delivered.

**Alexandria/Fairfax/Mount Vernon**  
703.776.3506

**Fair Oaks**  
703.391.4145

**Loudoun**  
703.858.6188

## Burial considerations

Here are some things to keep in mind if you are planning for a funeral and/or burial:

**Casket.** The size and style of the casket may affect the cost.

**Direct burial.** Many funeral homes can arrange a short, private viewing for immediate family members before a direct burial. Services can be held at graveside or in a place of worship or spiritual significance.

**Church/community burial.** Some churches maintain burial land for their members that is free or available at a reduced rate. Some towns and cities have community-owned cemeteries that may have available space at a lower cost.

**Viewing/funeral home.** This usually means one- or two-days’ use of a room in the funeral home for greeting friends and relatives. Viewing may also be held in your church, home, or other facility. Services may be held at the funeral home or another site before the graveside service.

**Cemetery.** Fees vary for the plot and the opening/closing of the grave. Cemeteries also sometimes limit the number of individuals who can be buried in one plot.

**Cremation.** While a casket is not necessary if there is no formal viewing, there are crematory and medical examiner fees. If formal viewing for friends and family is desired before cremation, a casket must be purchased or rented. Most funeral homes will allow a short, private viewing (for family members only) before direct cremation. Cremation remains may be kept in an urn, or even a necklace, or other keepsakes, or they may be buried or scattered. Check with the local authorities or your funeral home regarding local customs and laws.

**Hospital cremation.** This is only an option if your baby was stillborn (born without a heartbeat), the hospital will perform the cremation at no charge. With this service, there is **no return of the baby’s ashes to you.**

# Financial matters

Funeral and burial expenses are typically paid for by the deceased's estate, family, or friends. We understand the cost of a funeral may be a burden on your family's resources. Some counties offer financial help to families that qualify. Normally, these funds only provide for basic cremation or burial services, and upgrades are not permitted.

Additionally, some counties or cities may require the family to use a specific funeral home for which the county or city has contracted services. Contact the social service agency in the county or city where you live for eligibility.

**For more information about social services agencies, please contact the Inova case management team.**

**Inova Alexandria Hospital  
Case Management Department**

703.504.3580

**Inova Fairfax Hospital  
Case Management Department**

703.776.3508

**Inova Fair Oaks Hospital  
Case Management Department**

703.391.4772

**Inova Loudoun Hospital  
Case Management Department**

703.858.8017

**Inova Mount Vernon  
Case Management Department**

703.664.7238

## Other finances

For help dealing with questions about Inova hospital bills, please contact the patient accounts team on **571.423.5750**.

# Organ/tissue donation

If you have a live birth, you can make decisions regarding the possibility of donation of organs and tissues. This is reviewed and identified on a case-by-case basis by Infinite Legacy and your provider if this is your personal wish. The donation criteria are typically dependent on how far along in the pregnancy you are and the weight of your baby.

Infinite Legacy is the organization we currently work with for organ donation. Visit **[InfiniteLegacy.org](https://www.infinitelegacy.org)** for more information about this organization.

# Hospital autopsy

An autopsy is a postmortem examination of the body, including the internal organs and structures, to assist in possibly determining the cause of death or the nature of pathological changes. An autopsy may also help physicians learn more about disease processes and treatments.

A hospital autopsy may be requested by your obstetrician and may be comprehensive or limited to a particular organ or system. When requested, eligibility will be determined, and the legal next-of-kin must provide consent and sign a permit before a hospital autopsy is performed. Families requesting an autopsy can receive information on private autopsy companies for an external autopsy through our decedent affairs offices.

When the autopsy is completed, a written report is issued, usually within eight to twelve weeks. The report becomes a permanent part of the deceased patient's medical records, the family may contact hospital's medical records department to request results. For eligibility and additional information, please contact the Office of Decedent Affairs where you delivered.

# Genetic studies

In some cases, a perinatal loss is suspected to be due to a genetic condition. If appropriate, genetic testing can be completed using a tissue sample from the baby to look for any genetic or chromosomal differences. The results can take several weeks to come back. Once completed, a report will be issued, and the results will be reviewed with you by a physician or genetic counselor. The information received from genetic testing can sometimes be helpful for determining recurrence risks and may assist with future family planning.

It is important to know that genetic testing is always optional. Opting for this type of testing may incur additional costs. You can contact your insurance company to ask about their coverage policy for genetic testing.

**Genetic studies need to be completed within the first four hours of delivery.** The test itself does not delay funeral plans or prevent an open-casket service.

# Paperwork

## Paperwork to be completed in the hospital

- 1. Report of fetal death.** This form is mandated by the Commonwealth of Virginia.
- 2. Body disposition form.** This form identifies where you want the baby to go – either to a funeral home or the hospital.
- 3. Birth certificate.** This form only needs to be completed in the case of a live birth. Payment is required for this document in the form of a personal check or certified money order.

## Paperwork to be completed at home

- 1. Certification of vital record form.** This form allows you to order additional birth certificates and death certificates (live births only). Once this form is completed, please mail \$12 for each certificate requested to:

Division of Vital Records  
P. O. Box 1000  
Richmond, VA 23218-1000

For processing questions, please call **804.662.6200**.

For stillbirth certificates, please go to **[VDH.Virginia.gov/Vital-Records](https://www.vdh.virginia.gov/Vital-Records)** then choose stillbirth certificate from the menu on the left of the page. This certificate is free of charge.



# Hospital resources

## Spiritual Care

Interfaith chaplains are available 24/7 to provide patients, families and loved ones with spiritual and emotional support. Chaplains provide grief support through empathetic listening, hold space for “why” questions related to faith, suffering or meaning-making—and help develop rituals from different faith traditions to honor moments of both life and death. This could look like a dedication or naming ceremony, Baptism, Tahneek, blessing, prayer, or something else entirely. Ultimately, the goal is to create a moment for spiritual and emotional connection which is meaningful for you.

An interfaith chapel is also located at each Inova Hospital and always available for meditation, prayer or simply a quiet space to reflect. To speak with a chaplain please see the contact information below.

**Inova Alexandria Hospital Spiritual Care Office**  
703.504.3852

**Inova Fair Oaks Hospital Spiritual Care Office**  
703.391.4624

**Inova Fairfax Hospital Spiritual Care Office**  
703.776.3767

**Inova Loudoun Hospital Spiritual Care Office**  
703.858.8462

**Inova Mt. Vernon Hospital Spiritual Care Office**  
703.664.7263

## Child life specialists

Child life specialists are trained professionals with expertise in helping babies, children, teens, and their families overcome life’s most challenging events.

They understand the dynamics of families going through a serious medical experience and are trained to help decrease the trauma associated with these experiences. They are well-versed in grief and bereavement and can support families in creating memories during a loss and building legacies to honor a beloved member of the family. They also play a vital role in educating caregivers, administrators, and the public about the needs of children under stress.

Child Life Specialists work in all areas of healthcare. During times of perinatal loss, child life specialists should be contacted when there are siblings involved. They can help facilitate a sibling visit to the hospital to say goodbye

or learn about death. They can provide memory-making activities and help explain death/illness to children and teens in a developmentally appropriate manner.

Child life specialists also provide vital resources to families to use once they leave the hospital to help children cope with grief at home.

**Inova Fairfax Hospital Child life office**  
703.776.6486

**Inova Loudoun Hospital Child life office**  
703.858.6937

## Helping children cope with death

Working through grief and adapting to loss is important for children. It is critical that family members and others recognize the needs of grieving children and help them access the appropriate resources.

- Be direct, simple, and honest. Explain truthfully what happened in terms that children can understand. Do not use euphemisms for death with children, as it can confuse them.
- Encourage the child to express feelings openly. Crying is normal and helpful.
- Accept the child’s emotions and reactions. Do not tell the child how he or she should or should not feel.
- Offer warmth, physical presence, and affection.
- Share your feelings with the child. Allow the child to comfort you. It is okay for children to see you cry.
- Be patient. Know that children need to hear “the story” and may ask the same questions again and again.
- Reassure the child that death is not contagious. The death of one person does not mean the child or other loved ones will soon die.
- Maintain as much normalcy, stability, and routine in the child’s life as you can.
- Listen to what the child is telling or asking you. Then respond according to the child’s needs.
- Allow the child to make some decisions about participation in family rituals (examples: visiting the hospital, photos with the sibling, the funeral).

They can participate as little or as much in the memory making or other activities/rituals with patients as they experience the loss.

# Lactation support

Due to hormonal changes that your body experiences during pregnancy and birth, you may notice some changes in your breasts around 3–5 days after delivery. This can be a sign that your body has started to produce milk. At a time that is already difficult, this tends to be a very challenging part of losing an infant and often takes many women by surprise. The body starts making colostrum as soon as 16 weeks of pregnancy, meaning that any infant loss after 16 weeks can result in the production of milk. Around 3–5 days postpartum, you may notice some discomfort or engorgement in your breasts, and at this point, there are two options of how to handle the incoming milk supply. Some women choose to stop their milk production and others choose to continue milk production for the purposes of donating milk to a milk bank.

- If you would like to stop the milk production:
- Wear a comfortable, supportive bra with optimal circulation 24 hours a day to minimize stimulation, which can increase milk supply
- Express a little milk if needed to relieve pressure, but only to the point where you can tolerate the fullness of your breasts
- Use ice packs on the breasts which can help reduce swelling
- Always clear with a physician first, but if approved, take anti-inflammatory medicines (like ibuprofen) to help reduce swelling
- Reach out to a lactation consultant for support
- Watch for signs of fever, pain, or discoloration of the breasts, and alert your **physician right away if you are experiencing any of these symptoms.**



Breast Massage and Hand Expression Following Perinatal Loss

- If you would like to continue milk production for the purpose of donating milk to a milk bank, reach out to your local milk bank to learn more about their screening processes. Donor milk can be used in NICUs for premature infants to help them avoid life-threatening illnesses.

There is no right or wrong way to handle your body’s milk production. Each option is valid, and your choice should be what is most beneficial to you during this challenging time. Please feel free to reach out to the lactation team in your hospital to answer further questions and to receive support.

**Fairfax Medical Campus Lactation**  
703.776.4402

**Loudoun Hospital Lactation**  
703.858.8072

**Fair Oaks Hospital Lactation**  
703.391.3908

**Alexandria Hospital Lactation**  
703.504.7867

**Inova Breast Feeding and Lactation Medicine**  
5713.472.4300

Contact your OB immediately if you have a fever, pain and/or discoloration of the breast/chest or early flu-like symptoms that do not go away with the above treatments. It could be a sign of infection and may require different treatment.

# Legacy Donation: Kings Daughters Milk Bank

“Donating your milk is a loving tribute that can contribute to your physical, emotional, and spiritual healing. It may even save another baby’s life. Some mothers donate the milk they already have stored in their freezers. Others begin pumping or continue the process of producing milk specifically to donate. We would like to make donating your milk as easy and comfortable as possible. If you are considering a legacy donation, please contact us for more information, support, and guidance.” –Children’s Hospital of The King’s Daughters.



Kings Daughters Milk Bank  
757.668.MILK (6455)  
[KDmilkbank@child.org](mailto:KDmilkbank@child.org)

# Understanding grief

Grief is complicated and there are many factors that determine the length and intensity of grieving. Be patient with yourself.

The following are some helpful recommendations in dealing with grief:

- Crying is a healthy expression of grief and releases built-up tensions for everyone.
- Physical reactions may include loss of appetite or overeating, difficulty sleeping, and lack of energy. You may also find it hard to concentrate on your usual activities. Try your best to take care of yourself.

- Reach out to trusted support including family, friends, clergy, and mental health resources.

– **Inova Women’s Behavioral Health 571.623.3542**

– Join a loss community or support group

- Feelings of guilt can be quite common after a loss. Be gentle on yourself.

Everyone’s grief is unique. Give yourselves and each other some grace.

- Anniversaries, birthdays, and holidays can be stressful times. Planning ahead can help you reduce stress and gain some control.

# The Inova Foundation

Thank you for considering giving to give back in honor of your loved one.

At Inova, we believe every person deserves compassionate care and equal access to safe, respectful childbirth experiences. At birth centers across the health system, our women’s health specialists have the expertise to care for families at any stage of pregnancy.

Unfortunately, when there is a loss of a pregnancy it can be devastating and overwhelming for a family, despite the best efforts of both the parents and the clinical care team. As families navigate their grief, there are many emotions. At Inova, we are committed to providing the highest quality, compassionate care to every member of the family during this time.

**The Kennedy Marie Kelly Legacy Fund** was established by Matt and Ellen Kelly to honor their beloved daughter, Kennedy. It provides a way for other families to celebrate their child’s legacy and support future families through their grieving process.

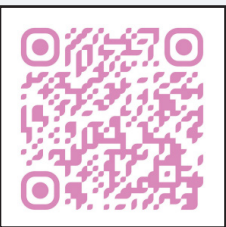
This fund has established and continued to support:

- **Family Support and Resources:** A loss of a child is one of the most difficult experiences a family can face. We strive to provide families with the support they need during their grief journey, including legacy-building,

memory making crafts and mementos for future loss families, annual memorial services, grief and support services.

- **Education for Our Team Members:** We equip our team members with the tools and knowledge to offer the most respectful and compassionate care to families experiencing loss. This includes training on communication strategies, grief response, memory-making, and supporting fellow team members. We are continually expanding and enhancing this education across the health system.
- **Specialized Equipment:** Thanks to the fund, we have been able to provide Caring Cradles throughout the Inova Health System, offering parents and families a comfortable way to spend time with their baby following a loss.

If you would like to donate or speak to someone about honoring the legacy of your loved one please contact Kirstin McArthur, Philanthropy Director,



**[Kirstin.mcarthur@inova.org](mailto:kirstin.mcarthur@inova.org)**

**[Inova.gives/KennedysLegacy](https://inova.gives/KennedysLegacy)**

Thank you for choosing to honor your child’s legacy by giving back to Inova and by supporting families as they go through their own grieving process.

# Notes/Questions



### Community perinatal loss support groups

Scan code or go to the website below  
for Inova's Women's Behavioral  
Health Team

[Inova.org/our-services/  
perinatal-mental-health](https://Inova.org/our-services/perinatal-mental-health)



### Postpartum Support International Helpline

**1.800.944.4773** (English & Spanish)

Text "HELP" to **800.944.4773** English

Text en Espanol **971.203.7773**

[Postpartum.net](https://Postpartum.net)

## Appointment Card

You can remove this card when you go to your first OB visit after your loss. When you check in, please hand this to the receptionist to share with your OB provider.

Thank you for your kindness during my appointment today. I have experienced a loss, and this is my first doctor's appointment.

The date of my loss was: \_\_\_\_\_

Today I am feeling:

\_\_\_\_\_  
\_\_\_\_\_

## DMA Choice

To reduce or stop receiving baby-related materials and offerings from companies, please contact **DMAChoice.org** and ask to be removed from mailing lists. Please note that your request may also affect other nonbaby-related mailings (e. g., catalogs and advertisements). Paid subscriptions will not be affected. There is a \$4 – 5 fee depending on processing choice.



**Inova Health System**