



gift of  
a lifetime

by Tammy Tate, RN, LCPC



Photographer: Sandy Puc

The Huene family embraced  
the time they had with Pearl.

The anticipation of a new baby breathes excitement into a family. But for some parents, joy is replaced with heartache when they learn that their much-loved preborn child may not survive. In the blink of an eye, they are thrust into a world of overwhelming grief, fear and despair.

If this is where you find yourself, this booklet was created for you. The information provided will address your fears and offer practical resources to assist you with making decisions.

# Heartbreaking News

You were there for a routine prenatal visit that turned into anything but routine. The doctor's words were shocking and completely unexpected. "Your prenatal lab results are back, and they confirm that your baby has a serious medical condition. I'm sorry, but there is no hope for survival."

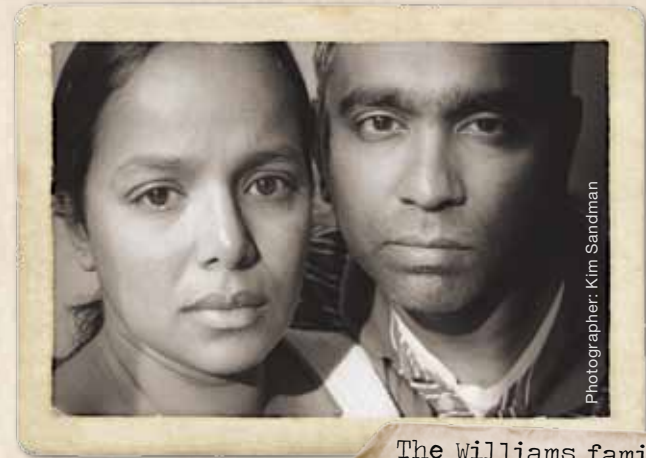
As you try to focus and listen to the doctor's explanation, you cradle your arms around your preborn baby, praying that this is all just a bad dream. You ask again, "Are you sure?" Your doctor confirms the results and then explains, "You have a decision to make—a decision to continue or end the pregnancy."



Micah Hezekiah  
Born July 15, 2010



*Your health-care professional may use other terms to describe the ending of the pregnancy, such as abortion, early induction of labor or voluntary interruption. Ask your doctor to explain what procedure would be used in your case, and how it would be done.*



Photographer: Kim Sandman

The Williams family placed their son in God's hands.

## A Difficult Decision

In less than an hour you have received devastating news, and now you face a critical decision. You may feel confused and overwhelmed, with a sense of urgency to settle the matter quickly.

Stop, take a deep breath and remember: Time is on your side. Give yourself a chance to digest the news and consider all of your options. Before making a decision, you may request that your health-care professional:

- Provide you with additional information about the diagnosis.
- Refer you to a maternal-fetal medicine specialist (also known as a perinatologist) for a second opinion.
- Provide you with a list of supportive services.

## Carrying to Term

The emotional pain and turmoil of a fatal prenatal diagnosis is very real, and it's only natural for everyone to want to "make it better." Many feel that ending the pregnancy is the best solution mentally and emotionally for the mom. However, research reveals just the opposite—that termination of a pregnancy in light of a fatal diagnosis can carry long-term psychological consequences and a risk for severe and complicated grieving.

Many couples will choose to carry their baby to term. They see this as a way to parent their newest family member and cherish whatever moments they have before and after the child's birth. Families call this a gift of time—time to affirm, honor and celebrate their baby's life.

Choosing to carry to term is not an easy decision for any parent, but those who have done so voice no regret. Parents often say they would do it again to relive the time they had with their baby, whether it was ten minutes or ten days.



Photographer: Michelle Souza



The Delgado family treasured the gift of time with their daughter.



Lauren Samantha (Sami)  
Born October 26, 2009

# Perinatal Hospice: A Journey of Hope

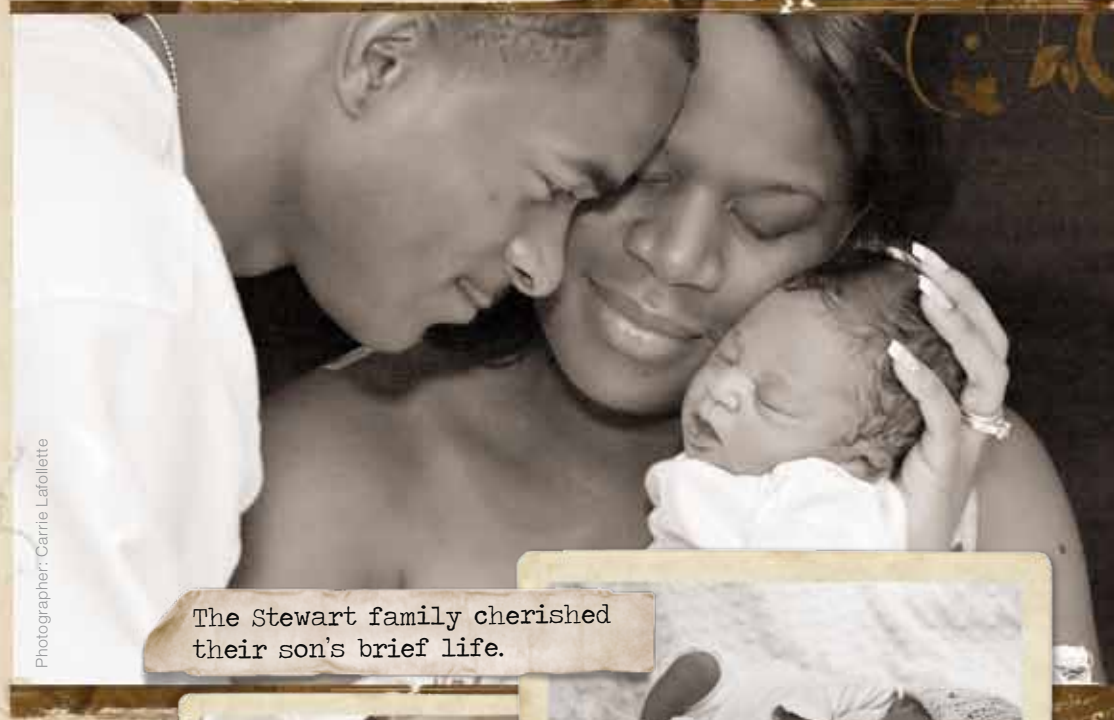
In the past, families who chose to carry their baby to term after a fatal diagnosis did so with little emotional or practical support. But today, they need no longer travel this road alone. Perinatal hospice care, a growing trend, can offer them help and guidance along the way.

Perinatal hospice is designed for parents who have received a devastating prenatal diagnosis and elect to continue the pregnancy, despite the likelihood that their baby will die before or after birth. It compassionately provides such families with the clear and relevant information they need.

*Simply stated, the perinatal hospice team comes alongside the family as they make meaningful plans to honor and celebrate the life of their baby.*

Perinatal hospice care begins at the time of diagnosis and continues through delivery and the bereavement period. It focuses on the emotional, physical and spiritual needs of everyone in the family. This is accomplished by an experienced team of physicians, nurses and counselors who plan and coordinate their efforts according to a family's particular situation.

If you decide on this path, it is important to choose an obstetrician who will support your wishes and walk through the process with you without criticism or disagreement.



Photographer: Carrie Lafollette

The Stewart family cherished their son's brief life.



Vayden James  
Born May 23, 2009



Photographer: Sandy Puc

The Haggard family spent precious moments with their son.

Maddux Achilles  
Born February 4, 2005

## Perinatal Hospice Care Will Provide:

### Practical Guidance

- Assist with the creation of a personalized birth plan that speaks to parents' wishes for the labor and delivery experience and care of their baby at birth.
- Provide coordination of services between different caregivers.
- Assist the family with the collection and preservation of keepsakes.
- Help the family plan a memorial service.

### Educational Support

- Provide parents with specific information about their baby's diagnosis.
- Help parents, as well as other family members, know what to expect throughout the grieving process.
- Offer private childbirth education classes and hospital tours.

### Emotional Support

- Provide grief support beginning at time of diagnosis.
- Offer referrals for pastoral care, as requested.
- Attend delivery at the family's request to serve as an advocate and to provide additional emotional support.
- Provide follow-up support throughout the bereavement period.
- Refer parents to a local perinatal bereavement support group.



Photographer: Audrey Imfeld

Pearl Jean  
Born June 5, 2006



The Huene family had a chance to say goodbye.

## Coping with Grief

Grief is a powerful and intense emotion, and it is especially painful when it involves the anticipated loss of a much-wanted child. There will be days when you are tempted to deny or run away from the pain, but the most healthy way to cope with your grief is to embrace it.

Be aware that women and men respond to grief differently. Women tend to cry and share their feelings openly, while men often hold their emotions inside. This difference, if not recognized, can create frustration and distance between partners. Open communication and the ability to accept and respect one another's grief response are the keys to maintaining a healthy relationship.

## It's a Family Affair

Sharing the news of the baby's diagnosis with your children can be difficult. Kids are great observers, and they easily sense when something is wrong. So, it is important to share with them what is happening. Withholding information in an effort to protect them may cause them to feel an overwhelming sense of guilt. They may feel they have done something wrong to cause your sadness.

### *Ways to relieve stress:*

- *Begin a journal.*
- *Eat healthily and regularly.*
- *Get plenty of rest.*
- *Stay active, read a book, go for a walk.*
- *Treat yourself to a massage or facial.*
- *Avoid the use of alcohol and drugs.*
- *Listen to music that is calming.*
- *Find spiritual comfort by praying, reading encouraging parts of the Bible and by talking with a friend, pastor or spiritual advisor.*

## Guidelines for sharing information with your children:

- Prepare what you will say and when.
- Tailor your explanations to each child's age and stage of development.
- Offer simple, easy-to-understand information.
- Avoid giving too much information.
- Expect children to respond according to their ability to understand.
- Offer reassurance that they did nothing to cause the baby's illness.

## Other ways to support your children:

- Encourage them to express their sadness.
- Maintain their routines.
- Solicit the cooperation of schoolteachers and other adults who have contact with your kids.
- Be open with your emotions. It is okay for them to see you cry.
- Involve them in a local grief support group for children.
- Share your spiritual beliefs, as they relate to death, in terms they can understand.
- Include them in family prayers for the baby and pray for their brother or sister by name.

## More and more families are encouraging siblings to become an integral part of the experience by letting them:

- Select the baby's name.
- Choose a special outfit or toy for the baby.
- Participate in family maternity pictures.
- Plan a birthday party for the baby.



Photographer: Steve Rubin

The Hollowell family is enjoying the unexpected months at home with Lilly.



Lillian Eva (Lilly)  
Born on July 4, 2010

[ Lilly's mom, Lisa, says, "Every day that Lilly lives is another blessing from God. But then, isn't that true for every one of us?" ]



Photographer: Audrey Imfeld

These Christmas ornaments with Pearl's footprints will grace the Huene family's Christmas tree each year.

## As you begin this journey of a lifetime . . .

The story of your baby's lifetime has already begun. Though the emotional pain cannot be underestimated, this journey of love and loss will change your heart and life forever. Perinatal hospice can help you find hope in the midst of your grief and give meaning to your journey.

Many parents find comfort and hope in knowing that their baby will know only tender care and love during his or her brief time on this earth. And at the moment of their child's last breath, they release their cherished baby directly into God's loving arms. May you find this same comfort and strength throughout your journey as you honor the life of your baby and build memories to last a lifetime.

## A Word to Family and Friends

Perhaps someone you know and love is facing the impending death of their baby. Naturally, you want to be very sensitive to their pain. Families often feel isolated and abandoned after receiving a terminal prenatal diagnosis. They may feel awkward trying to explain their baby's condition and therefore pull away in an effort to protect their emotions.

As a family member or close friend, you may feel equally uncomfortable. You are afraid you will say the wrong thing or create an awkward silence. These situations can sometimes cause you to also retreat, but don't. Your loved ones need you. They want to know that you care about them and their baby.

### Simple ways to show you care:

- Acknowledge their baby and call him or her by name
- Be supportive of the family. Accept their decisions without expressing judgment
- Prepare a meal
- Offer to run errands or clean the house
- Offer child care so Mom and Dad can have a night out
- Ask if you can help to coordinate the efforts of others wishing to help
- Remember to listen, be gentle and be available when needed
- Tell them that you are praying for them and think of them often

## Gift of a Lifetime is dedicated to:

Lauren Samantha (Sami) Delgado  
Maddux Achilles Haggard  
Lillian Eva (Lilly) Hollowell  
Pearl Jean Huene  
Vayden James Stewart  
Micah Hezekiah Williams

With warm thanks to the families who allowed their precious photos to be used to illustrate this booklet. Your willingness to help other families facing an adverse diagnosis is a lasting memorial to the lives of your sweet babies. Thank you for sharing these private family moments with us.

## Recommended Resources:

### ***Journey of a Lifetime*, by Tammy Tate, R.N.**

A guidebook for parents who have received a terminal prenatal diagnosis. From creating birth plans, to ideas for special keepsakes, this guide is a valuable resource to help parents make meaningful plans to celebrate and honor their baby's lifetime. The author founded Carolina Perinatal Support, which provides a bridge of support for families experiencing an adverse prenatal diagnosis that will likely result in a preborn or newborn death. Through practical guidance, education and compassionate support, they seek to relieve emotional suffering, while preserving the dignity and integrity of the family as they make meaningful plans to honor the life of their baby. [carolinaperinatal.com](http://carolinaperinatal.com)

### ***I Will Carry You: The Sacred Dance of Grief and Joy*, by Angie Smith**

The powerful story of a mother who carried a child deemed “incompatible with life,” and the eternal insights gained from a baby that lived less than three hours on earth.

### ***String of Pearls***

This organization offers practical guidance and compassion to families who find themselves on the darkest road they have ever walked. Founder Laura Huene, BSN, RN, has walked this road herself and now walks alongside other families as they make plans to honor their baby's precious life, saying hello and goodbye all in one breath. [stringofpearlsonline.org](http://stringofpearlsonline.org)

### ***GriefShare***

A grief recovery support group where you can find help and healing for the hurt of losing a loved one. [griefshare.org](http://griefshare.org)

### ***PerinatalHospice.org***

A helpful website for families and health care professionals that offers a list of hospitals, perinatal hospices or perinatal palliative care programs, for families who wish to continue their pregnancies with babies who likely will die before or shortly after birth.

### ***Now I Lay Me Down to Sleep***

At a family's request, a NILMDTS Affiliated Photographer will come to your hospital or hospice location and conduct a sensitive and private portrait session. The portraits are presented to the families on an archival DVD or CD that can be used to print portraits of your cherished baby. This network of more than 7,000 photographers in the United States and 25 countries, graciously volunteers their time and offers their services at no cost. For more information, visit [NILMDTS.org](http://NILMDTS.org). (*Photos in this booklet are used with the gracious permission of families whose photos were taken by photographers volunteering their time and expertise through NILMDTS.*)

More comfort care and helpful resources can be found at [FocusOnTheFamily.com](http://FocusOnTheFamily.com)—search for “perinatal hospice”.

## Sources

Calhoun BC, Napolitano P, Terry M, Bussey C, Hoeldtke NJ. “Perinatal hospice: Comprehensive care for the family of the fetus with a lethal condition.” *Journal of Reproductive Medicine*. 2003 May; 48(5):343-8.

Calhoun BC, Hoeldtke NJ. “The Perinatal Hospice: Ploughing the Field of Natal Sorrow.” *Frontiers in Fetal Health*. 2000; 2(5).

Kersting A. et al. “Psychological impact on women after second and third trimester termination of pregnancy due to fetal anomalies versus women after preterm birth—a 14-month follow up study.” *Archives of Women's Mental Health*. 2009 August; 12(4):193-201.

Kersting A et al. “Grief after termination of pregnancy due to fetal malformation.” *Journal of Psychosomatic Obstetrics and Gynecology*. 2004 June; 25(2):163-9.

Kersting A et al. “Trauma and grief 2-7 years after termination of pregnancy because of fetal anomalies—a pilot study.” *Journal of Psychosomatic Obstetrics and Gynecology*. 2005 March; 26(1):9-14.

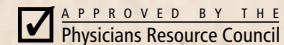
Leon, Irving G. “Pregnancy Termination Due to Fetal Anomaly: Clinical Considerations.” *Infant Mental Health Journal*, 1995, Volume 16: 112-126.

Leuthner S, Jones EL. “Fetal Concerns Program: A model for perinatal palliative care.” *MCN The American Journal Maternal Child Nursing*. 2007 September/October; 32(5):272-278.

Zeanah CH, Dailey JV, Rosenblatt MJ, Saller DN Jr. “Do women grieve after terminating a pregnancy for fetal abnormalities? A controlled investigation.” *Obstetrics and Gynecology* 1993 August; 82(2):270-5.

## FOCUS ON THE FAMILY®

© 2010 Focus on the Family



*Photographs on front and back cover: Pearl Jean Huene, Photographer: Audrey Imfeld.*

### **Author's Note:**

**Tammy Tate is the co-founder and CEO of Carolina Perinatal Support Network. Her 30 years of experience as a registered nurse in the field of high-risk obstetrics has given her great insight into the plight of parents faced with a terminal prenatal diagnosis. Tammy provides consulting services and training resources to groups who are establishing perinatal hospice programs. For more information, you may contact her by e-mail: [ttate@perinatalsupport.com](mailto:ttate@perinatalsupport.com).**



5009856