



# Pregnancy Loss

Bereavement support and resources  
for miscarriage, stillbirth and infant loss.



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 Catholic Health



## A Mother's Journey of Loss and Love

That little foot is my sweet Austin, born December 6, 2013, and yes, that's an actual heart on his foot. I started my journey as a mother in 1999 with the birth of my first son. My only daughter followed behind in 2001. What my journey thus far had taught me was that 9 months of pregnancy resulted in a baby. I never thought the depth of baby loss would find me, but it did in 2005. I had a blighted ovum and was assured it was a fluke thing. I hoped they were right! I went on to welcome a sweet healthy boy in 2006. Surely my loss was a fluke.

In 2008 I went in to my 16 week appointment to hear the words no parent ever wants to hear. "We cant find a heartbeat. I'm so sorry." As I sought options, grieved, cried, etc... I was introduced to Footprints on the Heart for the first time. After I gave birth to my sweet tiny son, I began attending regular meetings and finding strength through other families who cried deeply with me. It was such a comfort. Later that same year I attended my October meeting with tears in my eyes as I had to share with my new friends that I was losing yet another baby at that very moment. A few days later I birthed my sweet tiny daughter and Footprints became my safe haven. Two losses in a few months span had taken its toll on my heart, but I was determined to press on.

I started attending their Hopeful Hearts group, for those pregnant or trying again after loss. This group was so full of hope! I formed lifelong friendships with those expecting with me again, and we all welcomed our safe arrivals in 2009. It was glorious! In 2012, I had to say goodbye to another sweet son at 17 weeks, and found myself back at Footprints where I knew I could grieve honestly, and in a raw way...the way I



needed to. Longing for one more child, I began attending Hopeful Hearts again in 2013, and found out we were carrying another healthy baby! I was overjoyed and looked forward to my monthly meetings. Being able to have hope, express fears, and gush over our birth plans was like balm to my aching heart. Thankful again, we all birthed our safe arrivals in 2013.

I invite you to meet that safe arrival and see that heart imprinted on his foot. He carried the depth of loss and the freedom of healing, all on display on that little foot. What a miraculous gift! Thank you Footprints for sharing this journey with us!

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# To the Child in My Heart

*Precious, tiny, sweet little one,  
You will always be to me.  
So perfect, pure and innocent,  
Just as you were meant to be.*

*We dreamed of you and your life  
And all that it could be.  
We waited and longed for you to come  
And join our family.*

*We never had the chance to play,  
To laugh, to rock, to wiggle.  
We long to hold you, touch you now  
And listen to you giggle.*

*I'll always be your mother,  
He'll always be your dad,  
You'll always be our child –  
The child that we had.*

*But now you're gone...  
But yet you're here.  
We'll sense you everywhere.  
You are our sorrow, and our joy  
There's love in every tear.*

*Just know our love goes deep and strong  
We'll forget you never –  
The child we had, but never had,  
And yet we'll have forever.*



# Introduction

*Losing a baby can be very confusing and difficult. You find yourself saying “goodbye” when you have hardly had a chance to say “hello.” There will be many things happening to you and many decisions you will need to make. This booklet was created with the input of bereaved parents like yourself in order to answer questions, provide support and be a resource during this emotional and overwhelming time. It is not necessary to read this entire booklet now. Focus on the Miscarriage/Stillbirth sections as well as How To Care For Yourself. The rest may be read at a later time, when you are ready.*

*Whether you are at the hospital or perhaps at home, maybe in a doctors office, please know that we are here for you and are comfortable with your tears and will share our tears with you as well. Nothing is as sad as losing a beloved baby and we are here to help you cope with this immense loss.*

*The booklet was created for you and your family as a compilation of information to help you through this experience. Our hope is that it provides you with the resources you need to help you through this difficult time. On behalf of Catholic Health, we wish to convey our heartfelt sympathy for your loss. Please let us know what we can do to be of assistance to you and your family.*

## Rights of a Parent When Your Baby Dies

1. To be cared for by a sympathetic staff who will offer choices and respect your feelings, thoughts and individual choices.
2. To be with each other throughout the hospitalization as much as possible.
3. To request genetic studies.
4. To have information presented in terminology understandable to you regarding surgical procedure, pathology report, etc.
5. To be provided with information or support resources that assist in the healing process, e.g. support groups, counseling, reading material and perinatal loss newsletters.
6. To observe cultural and religious practices.
7. To be given the opportunity to see the baby if delivery occurs prior to surgery.
8. To understand options regarding choices about the care of your baby's body.

## Ectopic Pregnancy

Conception normally occurs when the sperm of the father unites with the egg from the mother in the mother's fallopian tube and travels down, implanting in the uterus. In an ectopic pregnancy the fertilized eggs implants somewhere else, usually in the fallopian tube, but occasionally in an ovary, in the cervix or the abdomen.

The causes of ectopic pregnancy are: pelvis infections, endometriosis, congenital abnormalities of the fallopian tube, previous tubal surgery, or adhesions from previous surgeries.

Ectopic pregnancy is different from other losses because, many times you are unaware that you were pregnant. You may have only discovered that you were in fact pregnant because of the pain that was caused by the embryo pushing on your fallopian tube.

If you did know that you were pregnant you may have started to notice some of the symptoms of pregnancy. If you did not know that you were pregnant you may have had pelvic pain, dizziness, fainting, or bleeding. Immediate medical attention is required because an ectopic pregnancy is potentially life threatening for

the mother. Your doctor will either use a drug called methotrexate or a surgical procedure called laparoscopy depending on your medical history and the immediate circumstances.

If you have to have your fallopian tube removed this may also be the loss of future pregnancies for you. This experience can be painful both physically and emotionally. A loss such as this can often result in a wide variety of emotions such as sadness, anger, guilt, relief or a sense of failure. Sometimes it can be difficult to talk to people about your loss because they were unaware that you were ever pregnant. This doesn't mean that you are not experiencing a loss and don't have the right to be sad and go through the grieving process.

An ectopic pregnancy is a complicated experience, as you often will have many losses to heal at the same time. Healing takes time, so be gentle with yourself. Some people need a few days and some need months or years. Give yourself the permission to do what you need during this time. Please remember that you can always call the coordinator of perinatal bereavement at the hospital that you were at for additional grief support resources.

# Miscarriage

## When Your Baby Dies Before 20 Weeks Gestation

When a fetal death occurs before 20 weeks of pregnancy it is called a miscarriage. After 20 weeks is considered a stillbirth (see page 6). You might hear your doctor or midwife say that you will have a “spontaneous abortion.” They might tell you that your miscarriage is “inevitable” or an “inevitable abortion.” The word abortion does not mean that you caused your miscarriage. These words mean that your miscarriage will happen no matter what. There is no way to keep you pregnant. Miscarriages occur in about 15-25% of all pregnancies, usually between the 7th and 14th weeks of gestation. Though you have a miscarriage, you are also having a birth.

## Learning You Will Miscarry

Please know that you are not to blame in any way. This miscarriage was not caused by something you did or ate or wished. Your body acted in a way that was beyond your control.

You might hear your doctor or midwife say that you have a “blighted ovum” or “chemical pregnancy.” This means that a lab test or a home test kit could tell you that you are pregnant. But an ultrasound (a picture of the inside of your uterus or womb) shows that the baby did not grow.

“Blighted ovum” is the most common reason for a miscarriage in the first three months of being pregnant. This means the baby began to grow but stopped. Most of the time your doctor or midwife will not know what caused your miscarriage. It is normal for you to want to have a reason. Not knowing might be hard for you. Some women cannot believe their pregnancy has ended until they start bleeding and cramping.

If you had an ultrasound, you can ask for a photo. Having your doctor explain your ultrasound to you might help you be sure that your pregnancy will end. You may need to have another ultrasound in which your doctor can compare the earlier ultrasound images with the later ultrasound images to show that the baby did not grow. If you had blood test, you can ask your doctor, midwife, or nurse to explain the test results. An ultrasound and/or a blood test will let your doctor know for sure that you will have a miscarriage. Take the time you need with your doctor to ask questions about your miscarriage.

## But I Still Feel Pregnant

Some women have a hard time believing that their baby has died because they still feel pregnant. Even after knowing that you will miscarry, you may continue to have

some pregnancy symptoms such as nausea, vomiting, tender breasts, fatigue or increased urinary frequency. This can be particularly difficult and confusing for some moms. With time, these pregnancy symptoms will begin to subside as your body recognizes that your baby has died.

## You Have Choices About How Your Miscarriage Will Happen

Your doctor or midwife will talk with you about what may happen after you’ve been told you are having a miscarriage. Here are the three options:

**1) Wait and see:** One option is to wait and see what your body will do on its own naturally or “spontaneously.” This likely means that you could deliver at home.

**2) Dilation and curettage (D&C):** A D&C means that your doctor opens or dilates the cervix (the opening to your uterus) and removes the pregnancy tissue. Your doctor or midwife may talk you about having this done as an outpatient in the hospital. Most people do not need to stay overnight in the hospital for this procedure.

**3) Medicine:** This option may include taking pills by mouth or by putting a suppository into your vagina. Both cause the uterus to cramp and empty. Your doctor might also want to use these medicines before a D&C.

We want to help you make the best choice for yourself. Whatever you choose (waiting, D&C, or medicine), we want you to give yourself time to adjust to the news about your pregnancy loss. Talk with your family, your health care team, or a spiritual advisor. They may help you decide what is best for you. It is okay to tell your doctor or midwife that you need more time.

Some women who learn they will miscarry may want a little time to pass. Other women want a D&C or pills the same day or the next day. In most cases, you do not need to decide right away. Several things can affect the timing.

**Emergency:** Your doctor or midwife will let you know if there are health reasons for you to take medicine or have your D&C at a certain time.

**Doing what works best for you:** You might want to arrange your D&C or taking your medicine based on:

- Your work schedule
- A time when someone can bring you into the hospital, stay with you, and then take you home
- The schedule of a certain doctor or midwife that you know and like



## Waiting to Miscarry Naturally

We cannot predict when your miscarriage will happen. In order for you to be prepared to miscarry at home, your doctor or nurse can give you supplies to help you be as comfortable as possible during your miscarriage. You can also use things you may have at home. Sometimes your doctor may want to do testing on some of the tissue that comes from your uterus. Talk to them about how they would like you to bring back the tissue to their office (a small plastic container with a lid or a plastic bag that zips).

## Supplies You May Need at Home

If you have been to your doctor or the emergency department, they may have sent you home with a miscarriage kit. This kit has supplies that you may need while you are miscarrying. This kit includes a piece of tulle to stretch across the toilet underneath the seat while you use the bathroom. This fabric will catch any fetal tissue that you pass. There is a small wooden box that you may use to bring your fetal tissue to the hospital for burial. Our hospitals keep the remains in a sacred, blessed place in our pathology department. Before you arrive at the hospital with the fetal tissue, please call one of our bereavement coordinators to arrange for this. We will respectfully keep your fetal tissue until our next burial service. Additional supplies you may also need:

- Sanitary pads to wear for bleeding.
- Plastic lined pads that can be put underneath you when you are sitting on furniture or lying on your bed can help prevent soiling fabrics.

## If You Miscarry at Home

After you pass the fetal tissue, you may have questions about what you should do next. There is no rush to do anything specific and you should use this time to do whatever feels right and comfortable to you. You may want to sit alone, be with your significant other to talk about what just happened, cry together, or pray together. There is no right or wrong way to experience a miscarriage. Some options that you have after you miscarry are:

- Take care of the fetal tissue yourself, in any way that you want.
- Bring your fetal tissue back to the hospital to be buried in our bi-annual memorial service. Call the hospital bereavement coordinator if you'd like to make burial arrangements for our memorial service.
- Plan your own memorial service and possible burial.

## Am I Bleeding Too Much?

You can expect to have some heavy bleeding and cramps after a miscarriage at home or after a D&C in the hospital. You may bleed enough to soak an entire full-size pad in an hour.

You should call or be seen by a physician right away if:

- Your bleeding is heavy enough to soak a pad an hour for 2 or more hours.
- You feel light-headed, as if you could faint.
- When you are sitting on the toilet, blood trickles out of your vagina for more than 3 minutes.
- You have trouble thinking straight.
- Your bed linens are soaked with blood.

If you think you are bleeding too much, call someone to be with you. If you are afraid, you should call 911 or be seen by a provider or come to the ER.

## Myths about Miscarriage

**Myth:** You will feel “all better” in a few days, weeks, or months.

**Truth:** Every person grieves differently. Healing is attained only after the necessary progression through the stages of grief and mourning.

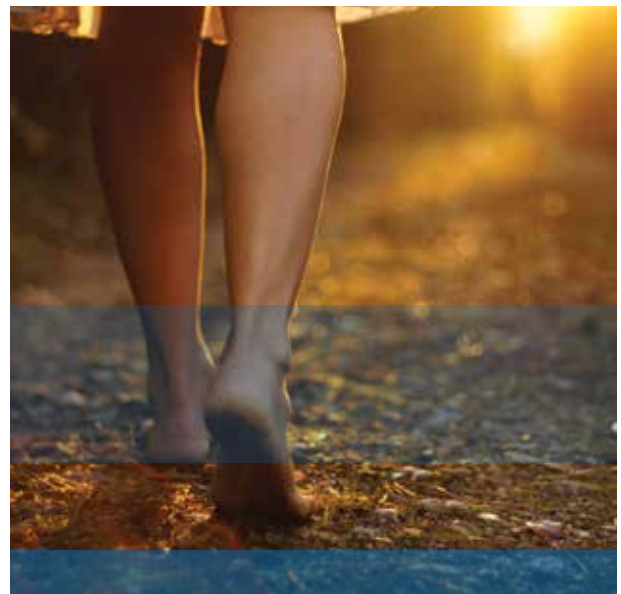
**Myth:** Grief is all-consuming.

**Truth:** In the midst of such an agonizing time in your life, there will be laughter. Do not feel guilty. Just as you allow yourself to grieve, allow yourself to laugh and smile.

**Myth:** Eventually you will accept the loss of your baby and forget about this awful time.

**Truth:** When you lose a baby, your whole future has been affected, not your past. No one can really accept that. But there is resolution in the form of healing and learning how to cope. Give yourself time.

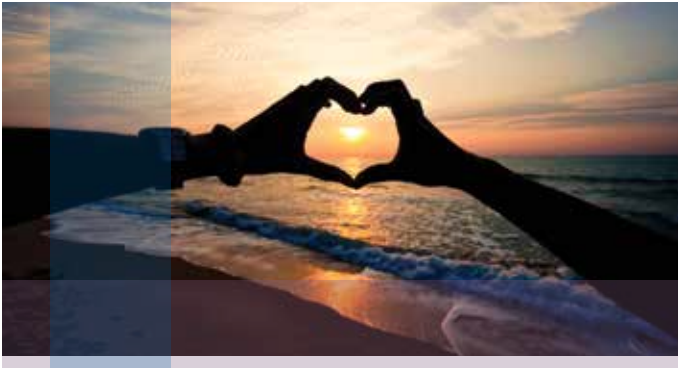
Your precious baby will have a place in your heart and you will always remember.



## Final Arrangements for Your Baby

### When Your Baby Dies Before 20 Weeks Gestation

If you are in the hospital and have had a D&C for a miscarriage or surgery for an ectopic pregnancy, the hospital will bury any baby remains at a site dedicated to miscarried babies. If your loss occurred at Sisters Hospital, your baby will be buried at Mount Olivet Cemetery, 4000 Elmwood Avenue, Kenmore, NY. If your loss occurred at Mercy Hospital, your baby will be buried at Holy Cross Cemetery, 2900 South Park Avenue, Lackawanna, NY.



After your pregnancy loss, the hospital keeps the remains in a sacred, blessed place in our pathology department. Two times a year Sisters Hospital, in conjunction with Mount Olivet Cemetery, holds a Memorial Service for all babies lost during pregnancy. Mercy Hospital works in conjunction with Holy Cross Cemetery. We will notify you of the first service being held after your baby's death. You may feel free to visit this site at any time. They are both beautiful monuments and have brought great comfort to many families who have faced the loss of their baby.

**Mount Olivet Cemetery:** To locate Section G of Mount Olivet Cemetery, approach the cemetery via Elmwood Avenue. If you are approaching from a southern direction (Buffalo), enter through the second cemetery gate on your right. If you are approaching from a northern direction (North Tonawanda), take a left at the first gate. After passing through the gate, stay on the cemetery roadway and pass three (3) sections on your right. Turn right into St. James Drive. The monument is located on the southern side of Section G.

**Holy Cross Cemetery:** The Annex Cemetery of Holy Cross is between Ridge Road and Dorrance Avenue. The monument is located in the McCauley Section on the northern side near the intersection of McKinley Parkway and Dorrance Avenue.

If you have any questions regarding memorial services please contact the coordinator of perinatal bereavement services at the hospital where you were treated.

## Your Reactions After Miscarriage

Each mother reacts differently following a miscarriage. You may be devastated, angry, depressed, feel guilt, or may feel that it is simply an experience that you just have to live through. You may grieve for the lost dreams of a future with an anticipated child. Some people do not develop closeness with the baby until birth so you may feel neutral. Other people think of a baby from the moment of conception. Any reactions and feelings are normal. It is just as normal not to grieve as it is to be devastated.

Following a miscarriage, you may have physical reactions:

- Fatigue
- Sleeplessness
- Sighing or exhaling loudly
- Heart palpitations
- Loss of appetite
- Headaches
- Nightmares
- Withdrawal from social activities

It is also common to have mood swings, which are partially due to the withdrawal of pregnancy-related hormones. You may have pain as your uterus contracts and the cervix or mouth of the uterus opens. You may also have spotting or bleeding with mild or severe cramping. Sometimes a dilation and curettage (D&C), may be necessary to prevent prolonged bleeding and infection.

After your pregnancy loss, your body may take weeks to return to normal. Uterine cramping may last for several days. Your breasts may be tender, and your milk may even come in. Vaginal bleeding may last for a week or more. If you have heavy bleeding, a foul discharge, or fever, promptly call your doctor or midwife.

One commonly misunderstood thought regarding miscarriage is that fathers don't hurt over this type of loss. Often concerns, sympathy cards, and condolences are directed to the mother. Fathers hurt too! Men express their grief in different ways than women and that's okay. Women by nature are more open with their feelings. Fathers sometimes feel that they are expected to be strong for their partner, be tender, compassionate, and caring at the same time. Men by nature do not always like to vent their feelings. So, they are more likely to "get busy" while they grieve by working extra hours, spending more time in the garage, or on outdoor projects. This behavior can be easily mistaken as a lack of caring. Fathers may have strong emotional ties to an unborn child or perhaps, do not. They simply express their feelings in a different way. So be open to understanding this difference between men and women.

# Stillbirth

## When Your Baby Dies After 20 Weeks Gestation

When fetal death occurs after 20 weeks of pregnancy, it is called stillbirth. These tragic deaths occur in about 1 in 160 pregnancies. Most stillbirths occur before labor begins. The pregnant woman may suspect that something is wrong if the baby suddenly stops moving around and kicking. A small number of stillbirths occur during labor and delivery.

An ultrasound examination can confirm that the baby has died by showing that the baby's heart has stopped beating. It sometimes can help explain why the baby died. The health care provider also can do some blood tests on the woman to help determine why the baby died. Some couples choose to have genetic studies and/or have an autopsy performed to try to determine why their baby has died. This is something that you can talk to your care provider about.

Your health care provider will discuss options with you about delivering your baby. Some women may need to deliver immediately for medical reasons. However, many couples can decide when they want to deliver their baby. Some choose to wait until the woman goes into labor. Labor usually starts within two weeks after the baby dies. Waiting for labor generally poses little risk to a woman's health. If labor has not begun after two weeks, providers recommend inducing labor because there is a small risk of developing potentially dangerous blood clots after this time.

Most couples choose to have labor induced soon after they learn of their baby's death. If the woman's cervix has not begun to dilate in preparation for labor, the provider may use vaginal medicine to help prepare her cervix. She is then treated with the hormone oxytocin (also called Pitocin), which is given through a vein. Oxytocin stimulates uterine contractions. Generally, a woman does not need a cesarean unless she develops problems with labor and delivery of the stillborn baby.

After delivery, the baby, placenta and umbilical cord are examined carefully to help determine why the baby died. The provider sometimes recommends an autopsy and tests to diagnose common chromosomal problems. In some cases, the provider recommends tests for specific disorders or various infections.

In up to half of all cases, these tests cannot determine the cause of stillbirth. However, information from these tests often is useful in helping couples plan a future pregnancy, even if the cause of the stillbirth remains unknown.

## Causes of Stillbirth

There are a number of known causes of stillbirth. Sometimes more than one of these causes may contribute to the baby's death. Common causes include:

- **Birth defects:** About 15-20% of stillborn babies have one or more birth defects. At least 20% of these have chromosomal disorders such as Down syndrome. Others have other birth defects resulting from genetic, environmental, or unknown causes.
- **Placental problems:** Placental problems cause about 25% of stillbirths. One of the most common placental problems is placental abruption. In this condition, the placenta peels away, partly to almost completely, from the uterine wall before delivery. It results in heavy bleeding that can threaten the life of mother and baby. Sometimes it can cause the baby to die from a lack of oxygen. Women who smoke cigarettes or use cocaine during pregnancy are at increased risk of placental abruption.
- **Poor fetal growth:** Babies who are growing too slowly are at increased risk of stillbirth. About 40% of stillborn babies have poor growth. Woman who smoke cigarettes or have high blood pressure are at increased risk of having a baby that grows too slowly. An ultrasound examination during pregnancy can show that the baby is growing poorly, allowing health care providers to carefully monitor the pregnancy.
- **Infections:** Infections involving the mother, baby or placenta appear to cause about 10 to 25% of stillbirths. Infections are an important cause of fetal deaths before 28 weeks of pregnancy. Some infections have no symptoms in the pregnant woman. These include genital and urinary tract infections and certain viruses, such as fifth disease (parvovirus infection). These infections may go undiagnosed until they cause serious complications, such as fetal death or preterm birth (before 37 completed weeks of pregnancy).
- **Chronic health conditions in the pregnant woman.** About 10% of stillbirths are related to chronic health conditions in the mother, such as high blood pressure, diabetes, kidney disease, and thrombophilias (blood clotting disorders). These conditions may contribute to poor fetal growth or placental abruption. Pregnancy-induced forms of high blood pressure (such as preeclampsia) also may increase the risk, especially when they recur in a second or later pregnancy.

- **Umbilical cord accidents:** Accidents involving the umbilical cord may contribute to about 2-4% of stillbirths. These include a knot in the cord or abnormal placement of the cord into the placenta. These can deprive the baby of oxygen.

Other causes of stillbirth include trauma (such as car accidents), postdate pregnancy (a pregnancy lasting longer than 42 weeks), Rh disease (an incompatibility between the blood of mother and baby), and a lack of oxygen (asphyxia) during a difficult delivery. These causes are less common.

Certain risk factors also are associated with stillbirth. Some of these include:

- Maternal age over 35
- Maternal obesity
- Multiple gestation
- African-American ancestry

A recent study found that African-American women had a two-fold increased risk of stillbirth compared to white women. It is not known why African-American women are at higher risk. The risk for Hispanic women was similar to that of non-Hispanic white women.

## Delivery of Stillborn at Hospital

Many people find the idea of seeing and holding their baby after delivery to be an uncomfortable one. However, it can be a very important step in your journey of grief. Parents who do not see their baby often feel incomplete or have a prolonged grief period. We encourage you to spend time with your baby after delivery and use that as a chance to say hello to your baby, before you have to say goodbye.

**THE HOURS AFTER DELIVERY ARE FOR YOU AND YOUR BABY!** Do not let anyone rush you through this time of saying hello and goodbye. We have rarely had parents tell us that they feel they spent too much time with their baby before or after death. Most parents only say they wish they had spent **MORE** time with their baby. If this becomes too intense or overwhelming then take a break and return later. We do not want you to feel rushed in any way and you don't need to say goodbye all in one day.

Some parents want to rush from the hospital after hearing such terrible news. Please know that we are comfortable with your tears and will share ours with you. Nothing is as sad as losing a beloved baby. Some parents think they will be able to say their goodbyes at the funeral home. This is true, but we encourage you to take the time, **NOW**, when you can **PARENT** your baby. These recommendations come from parents who have also experienced the death of their babies. This is a place to start and we encourage you to voice your special requests.

## Suggestions for Parenting Your Baby

- Name your baby and call them by their precious name.
- Hold your baby as he/she dies and say goodbye in private.
- After the baby dies, spend unlimited time together in a private room near the unit.
- Invite extended family members to come and visit, including siblings of all ages.
- Unwrap your baby and examine his/her every feature.
- Hold, rock, or lie with your baby.
- Give your baby a sponge or tub bath.
- Massage your baby with baby lotion.
- Clip fingernails, comb hair, do mouth care.
- Dress your baby. (You can bring in an outfit from home if you wish, or use clothing provided by the hospital).
- Have a pastor/priest/chaplain baptize your baby or have a naming/blessing/dedication ceremony.
- Sing lullabies or read stories to your baby.
- Let each parent have some time alone with the baby.
- Allow the staff to help you create memories such as pictures, footprints, or keep a lock of hair.
- Take family pictures – take video with your camcorder (you can **NEVER** have too many family photos).
- Discuss funeral plans with your family and bereavement coordinator or nurse.
- Do **ANYTHING** that is important to you and your family.

## Photographs

Photographs are such an important part of the journey of grief once you leave the hospital. Sometimes families are uncomfortable with the idea of having photos taken at such a sad time in their lives. Our experience working with many bereaved families has taught us that photographs become some of the most cherished memories that they have of their baby.

Many moms and dads have relayed that they were in such a state of shock when they delivered their baby that they do not remember details about what their baby looked like and it is only because they had photos that they were able to recreate those moments in their memory. The hospital will take digital photos of your baby. A digital copy will be created for you to take home. You may choose to leave the digital copy in a box forever or you want to look at your pictures right away. Please bear in mind that there is no right or wrong way to grieve and that whatever you choose to do, it is the best choice for you at that time.



# Newborn Death

## When Your Baby Dies After Birth

The news that your baby has a severe problem that will result in death is devastating. If you were given this news early on in the pregnancy you may have been given a choice to end your pregnancy, and you chose not to. Or you may not have known about your baby's medical issue until birth. Lastly you may have known about your baby's medical issues prior to delivery but at the time of birth they may have been more severe than doctors had originally thought. Whatever brought you to this point, you are now being faced with your newborn dying and we here at Catholic Health want to make sure that you and your baby receives as much comfort and respect as we can give you at this difficult time.

If your baby was born alive and moved to our Neonatal Intensive Care Unit (NICU) to be cared for you may have thought that with all the advances in modern medicine that your baby would survive. You may have anticipated a long stay in the NICU but never considered that your baby may die. Many parents feel this way and experience shock when they are told that their doctors do not have the ability to "save" their baby from whatever medical affliction they are suffering. Please take the time to ask as many questions as you have to make sure that fully understand your baby's condition. Making life and death

decisions is very difficult and it is important to consider all aspects of this choice. Consider this decision from an emotional, spiritual, and financial standpoint. It is important to remember that whatever decision you to come there will be emotional turmoil afterward, because there are no easy resolutions in such a circumstance.

Spending time with your baby before and after death is a very important step in the process of saying hello and goodbye to your precious child. You will not be rushed in the time you have with your baby as we recognize the importance of the limited time that you have with them.

If you are in the NICU and withdrawing support from your baby you may be present throughout the entire process. Our staff will assist you in holding your baby, placing your baby skin to skin if you desire, bathing your baby, dressing your baby, photographing your baby and making other memories with you. Please refer to page 7 for other ideas about parenting your baby during this precious time.

You will have many decisions to make after your baby has died in regard to their final arrangements. Please refer to pages 11-13 for information on burial, cremation, memorial services and autopsy.





# Multiples: Loss of One or More

## When One or More of Your Babies Die

The death of a baby is a tragic event. The death of one or more multiples presents a particularly complicated situation. As a parent you are faced with both a joyous and devastating scenario at the same time. This can be particularly difficult because you may feel as though you are riding an emotional roller coaster. You are both loving and grieving at the same time. The opposite emotions pull on you in drastically different ways and can be very painful.

A pregnancy involving multiples is often a once in a lifetime event. Often families who have had fertility problems find out that they are expecting multiples and are overjoyed. Parents as well as family and friends are often fascinated with the prospect of bringing home more than one baby. The devastating news that one or more of your babies has died is very overwhelming for parents.

If you know that one of your babies will not survive you may want to consider creating a birth plan so that the hospital staff is able to meet your needs to the best of our ability.

When thinking about your delivery and time after birth please consider the following:

- Who will be present?
- How much privacy do you need during this process?
- Will you photograph the babies together?
- Would you like a blessing or baptism performed together for the babies?
- How do you want to use your limited time to say hello and goodbye to your precious baby?
- Will you have your baby buried or cremated? Will you have a funeral or memorial service? What cemetery will be your baby's final resting place?

Grieving the loss of a baby is not something that you get over, it is something that becomes woven into the fabric of your family and who you are as parents. This process has no time line and may be delayed for many parents as they are so busy tending to their other child/children that they simply do not have the time or emotional capacity to grieve immediately after the birth.

If you have a surviving baby/babies it is suggested that you talk to them about their sibling that died. This is of course an individual decision but research suggests that multiples often have a feeling that something is missing from their lives. It can be comforting to many surviving multiples to realize that what they thought, was in fact true, and that they did indeed have a sibling.

Losing one multiple is often complicated by the fact that the surviving baby will be a constant reminder to you of your other baby. Milestones such as birthdays, graduations, and holidays will serve as a reminder that someone is missing from your lives.

The journey of grief is not an easy one and there is no one right way to reach a place of healing. If we can be of any assistance to you on this path please call and we are more than happy to help in any way that we can.



# When Your Baby has a Life Limiting Diagnosis

While the majority of expectant parents are planning for the arrival of their baby and planning for future birthday parties, vacations and memories to be made, you are in a different circumstance. You may have just been given the news that your baby has a lethal anomaly and will die shortly after birth.

While there is often no way to know for sure how long your baby will survive, what we do know is that preparing in advance for their birth can help you to make sure that all the things that you want to happen in that short time can be set up ahead of time.

Our staff works in conjunction with Essential Care for Children, a program of the Center for Hospice & Palliative Care. Together we can help you to develop a birth plan, seek physician consultation and offer you emotional support as you prepare for the birth of your baby.

## Essential Care for Children

Essential Care for Children is a home-based palliative (symptom control) care management program that provides coordination of medical services, psychosocial and spiritual support to children and their families. From diagnosis to remission or through advanced illness, Essential Care is available to help care for your child and family. Nurses, social workers and allied health professionals provide regular home visits, helping to minimize hospital stays and emergency room visits.

The Essential Care team includes registered nurses, child and adolescent specialists, music therapists, social workers, bereavement counselors and pastoral care counselors. They are all trained to work with infants, children and adolescents.

Essential Care for Children provides services for children who may have the following conditions:

- Cancer
- Degenerative neurologic conditions
- Congenital Heart Disease
- Immune deficiency
- Birth anomalies
- Metabolic disorders
- Other serious conditions

Services for Children, Teens and Families

- Admission evaluation in the hospital or at home
- Care coordination across medical settings, such as from hospital to home
- 24 hour, 7 day a week on-call availability by pediatric registered nurses

- Links to your primary physician, clinics, speciality disciplines, community services and financial assistance programs
- Pain and symptom control consultation
- Physician consultation for palliative (symptom control) care and symptom control in the hospital and home
- Emotional support for the patient, siblings and family members provided by all disciplines
- Social work and counseling at home
- Child Life Specialists: uses age-appropriate play, role modeling, games, music, and art to ease your child's and/or sibling's fears and to offer support
- Music and Massage Therapists\* utilize various pediatric-specific massage and music techniques to address individual physical, developmental, emotional, and mental challenges as a means of expression and comfort, contributing to a meaningful and nurturing environment for the entire family.  
*\*Evaluations performed upon clinical indication of need*
- Pastoral care and volunteer support for families in the home
- Grief counseling/support groups and educational programs

## Family Support

At Essential Care for Children, we have social workers who will focus on your needs as a parent. We'll help you maintain your balance – whether you just need some quiet time, or you need help understanding your medical bills, or you need financial assistance. Counseling is available in the home, and social workers can also refer you to community resources.

We can also help you with coordinating the following:

- Home health agencies
- Physical, occupational, speech, respiratory and nutrition therapies

## Perinatal Program

The Essential Care Perinatal Program is offered to expectant parents whose baby is diagnosed with a life-threatening condition before birth. Our perinatal program helps the expectant parents and families prepare for and cope with physical, emotional and spiritual issues through support and education at the time of diagnosis through the remainder of the pregnancy.

**You can call Essential Care for Children directly at (716) 686-8006 to help you set up services and discuss insurance coverage eligibility.**

# Making Final Arrangements for Your Baby

## Consent Forms

You may be asked to sign some consent forms. If you are in the hospital, please consult with your nurse if you have questions. If you are home and have questions, please ask your doctor or midwife. These forms may include:

- Recognition of Life request
- Undertaker release form
- Autopsy consent
- Certificate of Still Birth
- Professional Photography consent form
- Perinatal Bereavement Network release

*Some of these forms are available starting on page 29.*

## Looking for Answers

### Autopsy

The days surrounding the death of your baby are very emotional and sometimes confusing. Not only do you have to cope with so many feelings, you also have to make decisions that you have probably never faced before. One of these decisions is about an autopsy or the examination of your baby's body after death. This means that your baby's internal organs will be examined for causes and factors contributing to their death.

We are only able to perform autopsy on babies older than 20 weeks gestation. If your baby is under 20 weeks, your doctor and/or our pathology department can do an anatomy scan of your baby to see if there are visible signs of what happened to your baby.

While the decision to have an autopsy performed is a difficult one, it may help to provide answers, although it is important to understand that having an autopsy does not guarantee results that will give answers as to why your baby died. It may give doctors the opportunity to learn more, perhaps preventing other losses similar to yours. During the procedure, your baby's body is treated with respect and dignity. An autopsy will not normally delay funeral or burial plans, nor would it interfere if you wish to have an open casket.

You will need to sign a consent form before an autopsy can be performed. There is no fee for an autopsy to be performed on your baby. Preliminary results are usually available within a few days following the procedure. Complete results, including microscopic studies, will take longer. You may not get all the results for a few months. If you choose to have an autopsy for your baby, you can work with the funeral director to coordinate arrangements.

Try not to feel pressure from family, friends, or professionals as you make this decision. You need to do what you, as parents, feel is right for you and your baby.

### Genetic Testing

Please consult with your doctor for information about genetic testing. Genetic testing is covered by some insurance companies. You can ask your nurse or doctor whether it will be covered for you. It typically takes between 2-4 weeks for results to be given to your obstetrician. You should call their office to get your results. It is important to bear in mind that genetic tests do not always give definitive answers to what may have happened to your baby.



## Final Arrangements for Your Baby

### When Your Baby Dies After 20 Weeks Gestation

We realize this is a difficult time for you and your family, and we will make every effort to help you through this time. We would like to keep you informed of the options you have regarding the disposition of your baby's remains. If your doctor ordered any tests for your baby, all the options are available after tests are completed.

If your baby is 20 weeks or older at birth, New York State requires that a funeral home be contacted and a burial or cremation be planned for your baby. Arranging for the funeral is often the beginning of saying goodbye. Be sure to make your own choices; do not let others make these decisions for you.

These personal choices will help your grieving and healing process and it's very important that you be a part of the planning and the service. If you need help contacting a funeral home, a bereavement coordinator or nurse from the hospital or your own minister/priest will assist you. Be aware that each funeral home may have significant differences in the cost and type of service that they offer. Blessings and baptism are available here at the hospital for your baby. If desired, you may spend time with your baby after the birth. Your nurse will ask about your wishes or desires.



## Cuddle Cot for Time with Your Baby

The Cuddle Cot is a specially designed electric cooling pad placed in a bassinet. Warm hospital rooms can accelerate the decline of the baby's body. The Cuddle Cot slows the process by gently and quietly cooling the baby's body. For many grieving parents at Sisters and Mercy hospitals, having this gift of time to dress, hold, and cuddle their baby provides comfort and peace.

We encourage you to spend as much time as you need with your baby as you make your decisions about the funeral. You may choose to send your baby away from your room and later ask to see the baby. You may choose to send your baby away and only see your baby later at the funeral home.

Please remember: When you leave the hospital, the funeral director will come to pickup your baby. If the funeral director takes the baby before you leave the hospital, please know that your baby will not be available for you to see again at the hospital and you can see your baby later at the funeral home. All testing desired by you or your physician will need to be completed before the baby is sent to the funeral home.

## Burial Options and Information

If at all possible, both parents should be involved in planning the funeral and memorial services. Parents who were overlooked in the planning process often say they felt uncomfortable with the choices others made for their child's services. Well-meaning relatives and friends may try to assume the burden to save the parents from the pain. While the process will certainly be difficult, it is also a critical step in the healing process.

## Selecting the Funeral Home

Base your selection on several factors. First, make some phone calls and speak with the funeral director. Be sure to tell him or her that you have just experienced the death of an infant. His or her attitude should be sensitive and gentle. If you feel a sense of "over" professionalism or they seem distant, please hang up and try another funeral home. Assuring that the director will be sensitive to your needs as a bereaved parent is *the most* important factor of choice. If you are unsure with the director's level of awareness and sensitivity, arrange to make a visit.

Upon arrival, consider the options that they have available to you. Remembering important issues such as location, flexibility of services, coordination options with clergy and the cemetery you have chosen, and the payment arrangements. Be sure to make your memorial desires clear to the director so they are able to coordinate the schedule and other arrangements according to your wishes. If it is too difficult for you to deal directly with the funeral director, ask a family member or trusted

friend to speak on your behalf to communicate and coordinate your requests for the memorial service and funeral arrangements.

## Funerals

There are two types of funerals. One is with your child's body present (so that family members and friends may have the opportunity to say good bye) the other is without your child's body present. If you choose to have your child's body present, consider decorating his or her casket with pictures of his or her family, stuffed animals, toys flowers or other items of memorial. A common myth surrounding a burial is that all bodies must be embalmed. This is your decision. Express your questions and concerns to your director.

## Cremation

If you are considering cremation, think about what you would like to do with your child's ashes before acting on your final decision. Most bereaved parents who cremate are very comfortable with their decision. If you do cremate, you may keep the ashes in an urn at your home, you may bury the ashes (interred) with a memorial headstone, or you may scatter the ashes at a special location. If you choose to scatter the ashes, we strongly recommend that you save a small portion of the ashes to keep. There are special boxes, cremation jewelry (see page 28), and mini urns that are available to keep a small portion of the ashes in if you decide to cremate. You may still have a memorial service for family and friends. It is a crucial component in the bereavement process.

Also please keep in mind that if you cremate, you can always visit Sisters Hospital's site at Mount Olivet Cemetery or Mercy Hospital's site at Holy Cross Cemetery as a place to go and remember your baby. Two times a year Sisters and Mercy hospitals hold memorial services for all babies lost during pregnancy. We will notify you of the first service being held after your baby's death. You may feel free to visit the site at any time. The cemeteries have beautiful monuments and have brought great comfort to many families who have faced the loss of their baby.

If you are feeling pressured into cremation either by a lack of funds, lack of time, or sheer confusion surrounding the decision making process, please ask a professional to assist you in that decision so that you do not have regrets later.

Some parents express that they feel "cheated" if they do not have a special place to go and care for their child's body. An occasional visit to the cemetery where your child is buried or where the ashes are placed can have a special healing effect, as many parents have expressed. It is an individual decision, however, either way we recommend much consideration be given to this subject.

## Memorial Service

For some families it is important to consider a memorial service whether you have made the decision to bury or cremate. You may choose anywhere to have a memorial service. For example, you may decide to scatter your child's ashes at a special location and you may have a memorial service, called a committal service, at that special location.

If you have other children, please include these siblings in the memorial service. Offer them an opportunity to speak or read a letter or a poem to their brother or sister. Encourage siblings to draw a picture or write a letter and allow them to place it in the casket with their sibling. Older siblings may want to help carry the casket at the cemetery. Including siblings in the service will grant them the realization of the death and also give them special memories they will carry their lifetime.

The memorial service can be directed by your clergyman or clergywoman, a staff member of the funeral home, or even a friend or family member. Please consider a video tape of the service and photographs. It may be painful to look at them right away, however, someday you may want to have them available to you. Consider songs that you would like to play, read poetry in memory of your child, and consider having your child baptized if you are religious and had not yet done so in the hospital.

## Ideas for a Special Goodbye:

- Choose a special song or poem to eulogize your child. Listen to the words several times and make sure that they have meaning to you. Print the words to the song on special paper and hand them out to friends and family at the memorial service.
- Bring special stuffed animal toys from siblings, cards and letters from siblings, or a special necklace for your child to be buried with. Choose a special outfit and a special blanket. Don't forget booties and perhaps a bonnet or headband (for a girl). Be sure they have removed your child's identification bracelet prior to burial for you to keep.
- If you elect to have a spiritual leader speak at the memorial service, it is a good idea to limit the sermon to 15 minutes. You have the right to ask about the format or outline.
- Mom and dad could write a letter to the child that can be read by a close friend or family member on behalf of the parents. The letter can be about the feelings of grief, loss, and love for the child.
- Open casket services help to make an infant more "real" to others.

- Spend time holding and rocking your child prior to the service. You certainly can take the baby out of casket and hold him or her.
- Ask others to send stuffed animals, toys, or books instead of flowers. After the services, you can donate to a local charity on behalf of your child (see page 28).
- Make a playlist of your own favorite songs so you are not limited to the choice of the funeral home.
- The parents should consider being present for the closing of the casket for the final time and riding to the cemetery in the hearse with the child.
- The family can request to shovel the first dirt. This is a therapeutic ritual for many. You may stay with your child until the cemetery staff have completely buried your child.
- A butterfly release, lantern release, or environmentally friendly balloon release is a warm tribute to the significance of the child's life. Consider this ritual at the very end of the ceremony.
- If possible, a ceremony at sundown is beautiful. Consider a grave side unity candlelight service. This is a service where one larger candle is lit and each person lights their candle off the main unity candle in honor of the child.

For more information on memorializing your baby and grief support, please see pages 27 & 28.





# When You Get Home – How to Care for Yourself

## Mother Care Following Vaginal Delivery

### Vaginal Discharge/Bleeding

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1. Expect vaginal bleeding for 4-6 weeks. Your flow may be heavy, red, and sometimes contain small clots. The color will change from red to pink to brown/tan, followed by a yellowish/clear discharge.
2. If your flow returns to red a week or two after you are home, you may be doing too much. Rest. If the flow continues to be bright red and you have heavy clotting notify your doctor immediately.
3. Your period will resume within one to three months following delivery.
4. No swimming, douching, tampons, or sexual intercourse until after your 6 week postpartum checkup.

### Perineal Care

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1. If you have an episiotomy or perineal tear, use the spray bottle with each pad change as long as there is discharge. Remember to pat dry your perineal area using toilet tissue in a front to back motion.
2. Showers are OK and soap may be used to clean the perineum.
3. You may use your bathtub as a sitz bath to help relieve stitches that may itch, feel tight, or uncomfortable while healing. Before using the bathtub, make sure it is clean. Fill the tub with 4-6 inches of warm water, get in, open the drain and turn on the warm water. Keep the drain open while the water is running.

### Bladder/Bowl Function

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1. Empty your bladder at least every 4 hours while you are awake.
2. Expect a bowel movement 2-3 days after delivery.
3. If you are experiencing constipation, it is important for you to drink 8-10 glasses of water a day and to eat plenty of fruits, vegetables, and foods high in fiber. Stool softeners and/or laxatives should be used as directed by your doctor only.

### Activity/Rest

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1. Try to rest as much as possible for the first two weeks following delivery.
2. No heavy lifting or housework until your postpartum checkup. Light household duties such as cooking or washing dishes are allowed after two weeks when you feel able.
3. For the first two weeks at home, do not climb stairs more than twice a day (unless the bathroom is upstairs). Carry nothing up the stairs for two weeks.

### Nutrition/Diet

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1. Your diet should consist of nutritious foods high in protein, fruits, vegetables, and whole grains.
2. Avoid processed foods, fast foods, refined sugar, and transfats.
3. Drink plenty of water and diluted fruit juice. Avoid caffeine, especially if sleep is a problem.
4. Continue your prenatal vitamin for at least one month after delivery.

### Hormonal Changes

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It is important to remember that your body is going through hormonal changes at this time. Sometimes these falling hormone levels may make you more prone to mild temporary depression, often called the baby blues, which may make it more difficult to cope with the sadness that you already feel. You need to know that these changes are normal and are not long lasting. If you have concerns or it seems to last for longer than a few weeks, call your doctor to discuss your feelings surrounding this issue.

### Sexual Intercourse

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1. No sexual relations until your postpartum check-up when your vaginal discharge and discomfort subsides. If you attempt to have sex too early you could acquire an infection.
2. Discuss with your doctor the use of contraception.

### When to Call Your Doctor

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1. Fever above 100 degrees Fahrenheit with chills.
2. Bleeding as heavy as it was right after birth, a sudden gush of blood, or large clots that don't stop with rest.
3. Foul smelling discharge, not the "period" smell.
4. Persistent pain in a specific area of the abdomen, chest, lower back, or legs.
5. Pain/burning or an unusual increase in frequency of urination.
6. Redness, drainage, increased tenderness, or an open area on your episiotomy/perineal tear repair.
7. Localized area of redness or tenderness on your breast with a fever.
8. Depression and/or anxiety where you feel you may be a danger to yourself or to someone else.

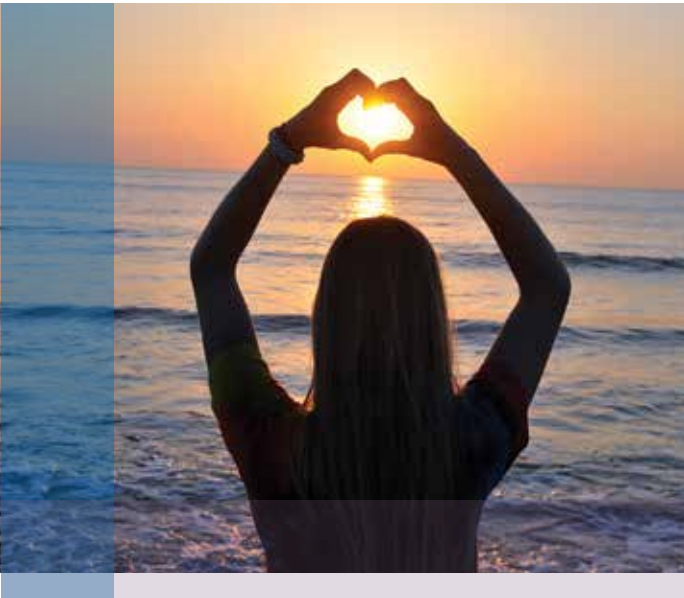
## Breast Care and Suppression of Breast Milk

Having your milk come in can be quite upsetting and a sad reminder that you don't have a baby to nurse. There are a number of things you can do to help minimize your milk production. Drinking water only for thirst (not excessively) will help minimize your milk.

A great deal of physical activity can stimulate milk production, which is another good reason for limiting activities in the early days. It is not recommended that you express or pump milk from your breasts to dry them up. This will only produce more milk and could make you more uncomfortable if your breasts become engorged.

You may want to wear a tight bra or even an ace bandage immediately postpartum to try to prevent milk let down. For soreness and tenderness, take an anti-inflammatory medication such as Motrin or Advil. Tylenol is also another good option for pain management if you need it.

Use cold compresses on breasts for comfort. You can put crushed ice in a plastic food bag covered with a cloth or put either a washcloth or a wet disposable diaper in the freezer and then put it on your breasts.



If your breasts become engorged, submerging them in warm water may help. Fill the bathtub with warm water, get on your hands and knees in the tub and lower your breasts into the water. While you may feel silly, after a few minutes the milk will let down to naturally release some of the pressure.

Do not massage or hand express the breasts. Leaking milk from the breasts is common and may last for several weeks after you get home.

Notify your health care provider if you are in severe pain, have a fever, or notice any red streaks or lumps.

## Sage and No More Milk Tea

Eating sage is one of the best ways to decrease milk production. No More Milk Tea is also another option to decrease milk production and is available at Baby's Sweet Beginnings in Lancaster, NY.  
[www.babyssweetbeginnings.com](http://www.babyssweetbeginnings.com) • (716) 681-8100

## Cabbage Leaf Treatment

Cabbage leaves have been used in some cultures for hundreds of years in the treatment of sprains, infections, and some breast problems. It has become popular in a number of hospitals and birthing centers for managing breast engorgement. There appears to be an unknown substance in the cabbage leaf that is absorbed through the skin. This unknown substance in the cabbage leaf causes decreased breast swelling and milk production. Most women find it to be very soothing on engorged breasts.

### METHOD:

- Wash green cabbage leaves well and dry.
- Store leaves in the refrigerator.
- Cut stalks from leaves (to prevent pressure on breast) and apply leaves to breast, avoiding nipple area.
- Remove when wilted, toss, and apply fresh leaves.

Cabbage leaves may stain your bra. Cease using leaves when engorgement settles or breasts feel more comfortable and breast milk is suppressed. Do not use if you have a history of an allergy to cabbage. Recommended use is for two to five days.

## Cabo Cream

This lotion is made from cabbage leaf extract and can be used immediately after birth to help decrease engorgement and the amount of breastmilk that your body will produce. The cream can be purchased online and overnight shipped or bought at Baby's Sweet Beginnings in Lancaster, NY.

[www.cabocrema.com](http://www.cabocrema.com)

[www.babyssweetbeginnings.com](http://www.babyssweetbeginnings.com) • (716) 681-8100

## Consider Donating Your Breast Milk

If you have breast milk that you have stored in the freezer or refrigerator, please consider donating it. You can drop off milk at Sisters of Charity Hospital or Mercy Hospital of Buffalo. We will freeze your milk and ship it to the New York Milk Bank, which will in turn provide it to a hospital Neonatal Intensive Care Unit. If you would like to become a donor, contact the New York Milk Bank at 212-956-MILK.

# Emotional Reactions and Grieving

## Responses To Loss

When we experience a loss, our reactions are not entirely predictable. Everyone reacts differently and no reaction is right or wrong. There are several types of responses to loss and they can be emotional, physiological, physical, and/or spiritual. Each of these response categories has the associated reactions listed below:

### Emotional Responses

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- Shock
- Disorganization
- Denial
- Panic
- Disbelief/Numbness
- Relief
- Guilt and Self-Blame
- Powerlessness
- Fear
- Anger/Rage
- Feelings of Loss/Loneliness
- Hopelessness
- Emptiness
- Shame
- Sadness/Depression

### Psychological Responses

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- Inability to Concentrate
- Lack of Interest
- Explosive Emotions
- Prolonged Withdrawal
- Low Self-Esteem

### Physical Responses

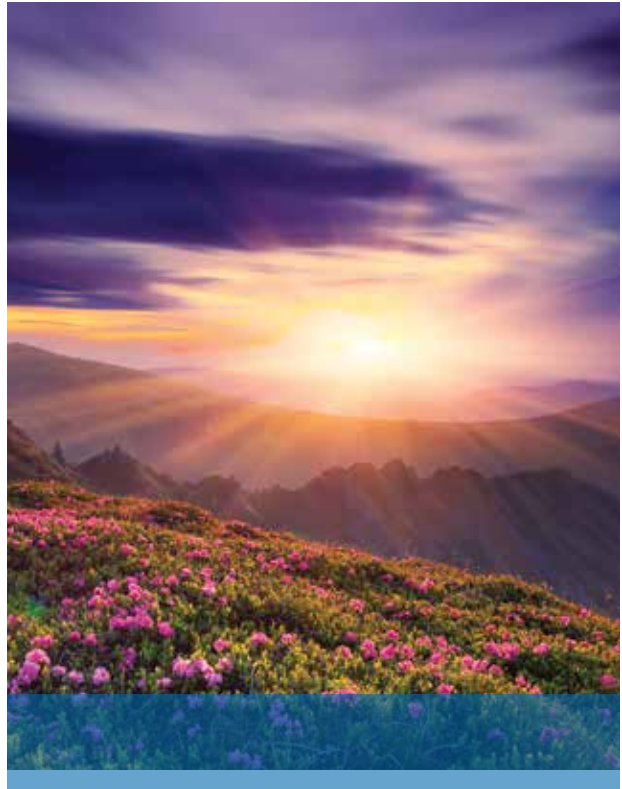
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- Tiredness/Lack of Energy
- Ulcers
- Difficulty Sleeping or Prolonged
- Heart Problems
- Periods of Sleep
- Stomach Pain
- Excessive Appetite or Lack of Appetite
- General Nervousness and Trembling
- Tightness in Chest
- Lump in the Throat
- Shortness of Breath
- Headaches
- Loss of Muscular Strength

### Spiritual Responses

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- Anger with God
- Changed Priorities
- Doubts about Belief System
- Search for Meaning in the Event
- Questions Regarding Meaning of Life
- Gratitude for Time Spent Together
- Interest in Afterlife
- Belief that Person is Happier, No Longer Suffering, in a Better Place, etc.



## Reconciling Your Grief

You may have heard, indeed you may believe, that your grief journey will end when you resolve or recover from your immense sadness. However, your journey won't end. People do not "get over" grief. They work through to a "new normal." This new normal we call reconciliation.

Reconciliation is a term that seems more appropriate for what occurs as the mourner works to integrate the new reality of moving forward in life without the physical presence of the person who died. With reconciliation comes a renewed sense of energy and confidence, an ability to fully acknowledge the reality of the death, and a capacity to become re-involved in the activities of living.

In reconciliation, the sharp, ever present pain of grief gives rise to a renewed sense of meaning and purpose. Your feelings of loss will not completely disappear, yet they will soften, and the intense pangs of grief will become less frequent. Hope for a continued life will emerge as you are able to make commitments to the future realizing that the person who died will never be forgotten, yet knowing that your life can and will move forward.

## Consolation

Here are a few ways that may help you during this time of your life.

**SOLITUDE HELPS.** You may need time to think about your baby, to remember your life as you prepared for your baby, and to consider how your life will be now. You may be overwhelmed by your sorrow. You may want to stay in bed and cry or sleep, or go for a walk, or sit in a chapel.

**OTHER PEOPLE HELP.** Friends and family members are likely to empathize with you. Even if they do not know what to say, just being with other people and talking can be supportive. Accept others invitations to participate in activities, but leave if you feel the need to. Reach out to family and friends for support when the next hour or day seems unbearable.

**ACCEPTING SUPPORT HELPS.** Others may want to help by doing things for you. They may want to bring you food, talk, or run errands for you. Accept these acts of kindness whenever you can.

**REST AND SLEEP HELPS.** Grieving can be exhausting. Take care of your body physically by getting enough to eat, drinking enough water, and sleeping enough hours.

**TIME HELPS.** Your life may never be the same again. Whatever your experience with death and dying, you will find that you see the world and your place in it differently.

**NATURE HELPS.** Take a walk and focus on something promising in what you see. Studies have shown spending time in nature has been effective in relieving and/or preventing depression and anxiety symptoms. Getting outside in fresh air is good for both your body and mind.

**CREATIVITY HELPS.** You might try writing about your feelings or creating a special area in your home to honor the memory of your loved one.

### Twelve Freedoms of Healing in Grief

<b>Freedom #1:</b>	You have the freedom to realize your grief is unique
<b>Freedom #2:</b>	You have the freedom to talk about your grief
<b>Freedom #3:</b>	You have the freedom to expect to feel a multitude of emotions
<b>Freedom #4:</b>	You have the freedom to allow for numbness
<b>Freedom #5:</b>	You have the freedom to be tolerant of your physical and emotional limits
<b>Freedom #6:</b>	You have the freedom to experience grief attacks or memory embraces
<b>Freedom #7:</b>	You have the freedom to develop a support system
<b>Freedom #8:</b>	You have the freedom to make use of ritual
<b>Freedom #9:</b>	You have the freedom to embrace your spirituality
<b>Freedom #10:</b>	You have the freedom to allow a search for meaning
<b>Freedom #11:</b>	You have the freedom to treasure your memories
<b>Freedom #12:</b>	You have the freedom to move toward your grief and heal



## Things To Do To Help Yourself

- Give yourself a certain amount of time each day to grieve (cry, talk about your child, look at pictures, connect with the pain).
- When you cry, cry from the depth of your being. When you scream, go to an enclosed area where no one can hear you and scream until you are exhausted.
- Understand that others cannot understand unless they have been through it.
- Each day accomplish at least one task (call a friend, go for a walk, make the bed, read a chapter from a recommended book, smile at someone, get your hair done).
- Remember that it is difficult for others to be around the constant pain of your grief, especially when your story is untold. Try to ask about the other person's life as well, so that the relationship is more balanced. We can never heal when only our story counts. We must also be willing to listen and respond to others and the situations of their lives.
- If you are having a difficult time sleeping or eating for more than a few weeks, it is important to contact your physician. You may need therapy and/or medication to help. Medication does not take the grief away, but it may soften some of the extreme responses so that you can focus more clearly and function more effectively.
- If you previously enjoyed walking or any other physical exercise, it may be beneficial for you now as you grieve. Grief is an energy that needs to be released and there are many ways to release it physically, artistically, musically, poetically, writing, creating something, woodworking, knitting, sewing, etc. Find what works for you.
- Learn something that is new to you and perhaps something that is related to helping you understand your grief, suffering, life, or a deeper understanding of your spirituality.
- Recognize that grief is carried with you throughout your life, but it is YOUR choice as to how it is carried. You may carry it as a "victim" (thinking you are the only one) or you may carry it as a "courageous warrior" (something that motivates you to view life as a challenge). If you choose the courageous warrior, you will begin to connect with all the suffering in the world and eventually you will make peace with your loss.
- Always be patient and gentle with yourself. You will survive and actually find hope again, but it is necessary to remain patient.

## *The Journey Through Grief – The Mourner's Six Reconciliation Needs*

By Alan D. Wolfelt

To get through these tough times, there are many things you can do for yourself or others. The death of someone loved changes our lives forever. And the movement from "before" to "after" is almost always a long, painful journey. From my own experiences with loss as well as those of the thousands of grieving people I have worked with over the years, I have learned that if we are to heal we cannot skirt the outside edges of our grief. Instead, we must journey all through it, sometimes meandering the side roads, sometimes plowing directly into its raw center.

I have also learned that the journey requires mourning. There is an important difference, you see. Grief is what you think and feel on the inside after someone you love dies. Mourning is the outward expression of those thoughts and feeling. To mourn is to be an active participant in our grief journeys. We all grieve when someone we love dies, but if we are to heal, we must also mourn.

There are six "yield signs" you are likely to encounter on your journey through grief— what I call the "reconciliation needs of mourning."

### **Need 1 – Acknowledging the reality of death**

This first need of mourning involves gently confronting the reality that someone you care about will never physically come back into your life again.

Whether the death was sudden or anticipated, acknowledging the full reality of the loss may occur over weeks and months. To survive, you may try to push away the reality of the death at times. You may discover yourself replaying events surrounding the death and confronting memories, both good and bad. This replay is a vital part of this need of mourning. It's as if each time you talk it out, the event is a little more real.

Remember, this first need of mourning, like the other five that follow, may intermittently require your attention for months. Be patient and compassionate with yourself as you work on each of them.

### **Need 2 – Embracing the pain of the loss**

This need of mourning requires us to embrace the pain of our loss, something we naturally don't want to do. It is easier to avoid, repress, or deny the pain of grief than it is to confront it, yet it is in confronting our pain that we learn to reconcile ourselves to it.



You will probably discover that you need to “dose” yourself in embracing your pain. In other words, you cannot (nor should you try to) overload yourself with the hurt all at one time. Sometimes you may need to distract yourself from the pain of death, while at other times, you will need to create a safe place to move toward it.

Unfortunately, our culture tends to encourage the denial of pain. If you openly express your feeling of grief, misinformed friends may advise you to “carry on” or “keep your chin up.” If on the other hand, you remain “strong” and “in control”, you may be congratulated for “doing well” with your grief. Actually, doing well with your grief means becoming well acquainted with your pain.

### **Need 3 – Remember the person who died**

Do you have any kind of relationship with someone when they die? Of course. You have a relationship of memory. Precious memories, dreams reflecting the significance of the relationship, and objects that link you to the person who died (such as photos, souvenirs, etc.) are examples of some of the things that give testimony to a different form of a continued relationship. This need of mourning involves allowing and encouraging yourself to pursue this relationship.

But some people may try to take your memories away. Trying to be helpful, they encourage you to take down all the photos of the person who died. They tell you to keep busy or even to move out of your house. But in my experience, remembering the past makes hoping for the future possible. Your future will become open to new experiences only to the extent that you embrace the past.

### **Need 4 – Developing a new self-identity**

Part of your self-identity comes from the relationships you have with other people. When someone with whom you have a relationship dies, your self-identity, or the way you see yourself naturally changes.

You may have gone from being a “wife” or “husband” to a “widow” or “widower.” You may have gone from being a “parent” to a “bereaved parent.” The way you define yourself and way society defines you is changed.

A death often requires you to take on new roles that had been filled by the person who died. After all, someone still has to take out the garbage and buy the groceries. You confront your changed identity every time you do something that used to be done by the person who died. This can be very hard work and can leave you feeling very drained.

You may occasionally feel child-like as you struggle with your changing identity. You may feel a temporarily heightened dependence on others as well as feeling of helplessness, frustration, inadequacy, and fear.

### **Need 5 – Searching for meaning**

When someone you love dies, you naturally question the meaning and purpose of life. You probably will question your philosophy of life and explore religious and spiritual values as you work on this need. You may discover yourself searching for meaning in your continued living as you ask “How?” and “Why?” questions.

“How could God let this happen?” “Why did this happen now, in this way?” The death reminds you of your lack of control. It can leave you feeling powerless.

The person who died was a part of you. This death means you mourn a loss not only outside of yourself, but inside of yourself as well. At times, overwhelming sadness and loneliness may be your constant companions. You may feel that when this person died, part of you died with him or her. And now you are faced with finding some meaning in going on with your life even though you may often feel so empty.

This death also calls for you to confront your own spirituality. You may doubt your faith and have spiritual conflicts and questions racing through your head and heart. This is normal and part of our journey toward renewed living.

### **Need 6 – Receiving ongoing support from others**

The quality and quantity of understanding support you get during your grief journey will have a major influence on your capacity to heal. You cannot, nor should you try to, do this alone. Drawing on the experiences and encouragement of friends, fellow mourners, or professional counselors is not a weakness but a healthy human need. And because mourning is a process that takes place over time, this support must be available months and even years after the death of someone in your life.

Unfortunately, because our society places so much value on the ability to “carry on,” “keep your chin up,” and “keep busy,” many mourners are abandoned shortly after the event of the death. “It’s time to get on with your life” are the types of messages directed at mourners that still dominate. Obviously, these messages encourage you to deny or repress your grief rather than express it.

To be truly helpful, the people in your support system must appreciate the impact this death has had on you. They must understand that in order to heal, you must be allowed to mourn long after the death. And they must encourage you to see mourning not as any enemy to be vanquished, but as a necessity to be experienced as a result of having loved.

# For the Fathers and Siblings

## Feelings

While this can seem like a time that is focused on mom and the baby you have lost, fathers are also grieving. Often fathers have all of the feelings that mothers have: sadness, anger, guilt, shock, helplessness, impatience, and anxiety. Losing your baby through a miscarriage or stillbirth is losing your hopes and dreams for that child. It is normal to grieve for never being able to teach your lost child how to play baseball, read, ride a bike, and many other plans you had for him throughout his life.



## Grieving Differently

A grieving father often looks different than a grieving mother because dads are probably attending to a lot of mom's physical needs. Men in our culture are taught not to cry and to be strong. This is a difficult task when your baby has just died. Many well intended people will probably ignore dad's needs and only ask how mom is doing. This neglects that fact that you too are grieving your child who has died. These types of messages encourage dads to deny their grief and subsequently not deal with the loss of their baby. While dads may not have the physical bond that mom had with your baby this does not lessen the emotional bond that you may have had. You are probably experiencing many of the same emotions that mom is feeling.

## Your Relationship

A lot of people think a child's death makes a couple closer. Actually, the opposite can be true. Parents can be so exhausted from their own grief that they cannot lean on each other. One of you may try to stay strong while the other grieves. Try to attend a local support group. Listening to others talk can help validate the array of emotions you may be feeling.

Nurture your relationship by carving out time for a date night; talk openly about your feelings not only from the miscarriage but about each other and your love. Hold each other. You or your partner might be scared or nervous for the first intimate sharing after your loss, possibly relating having sex to the possibility of another loss. Treat each other gently. Some fathers feel apprehensive about making love to their wives after a loss. They may feel as though they do not want to be responsible for putting their wives in a position of being pregnant again and possibly another loss. Talk to your wife if you have these feelings; they are completely normal.

Remember no two people grieve alike; you and your partner will experience it and cope differently. Respect each other's grieving process.

## Coping

**Talking.** Some men are uncomfortable talking as much as mom wants to. Dads may think that by talking about the baby or the event, that they are triggering mom to be upset again and many choose to be quiet and keep their feelings to themselves. Moms often view this silence as a detachment from their baby and feel as though the dad was not as invested as she was or does not care that the baby died. It is important to find other ways of expressing your emotions if you cannot do it through verbal communication.

Talking about your baby can help you grieve. You may have memories of when you and your partner both found out you were expecting a baby, hearing your baby's heartbeat, seeing a sonogram picture, the plans you had for your child, and even the death/miscarriage experience. You will have questions and concerns just as mom does, and you also need someone to listen and be supportive to you when you want to talk about it. Ask for what you need; a mom may not know how to best help you through your journey of grieving.

It may be difficult to talk, but try to talk a little bit each day. Talking might help lessen your pain, clear the anger you may feel, and validate your feelings.

**Collect Information.** It may be helpful to ask your doctor questions, seek information from a high risk specialist like a perinatologist and go over a pathology report (if there was one) as a means of learning about infant loss. Talking to your doctor may explain what happened and what may happen in the future. You may never get concrete answers to all of your questions, but gathering facts and information can help you and your partner feel some sense of control.

**Writing.** To help you sort out your emotions and feelings after the loss, write a letter to your baby. You can write about who you and your partner are, how much you wanted to watch him grow up, care for him, and hold him. If you're having a difficult time expressing your feelings, writing them down can help you cope with your loss.

**Memorializing.** Start a memory box for your baby. Include items like a certificate of life, any sonogram pictures you may have, your letter, journal entries, and any small mementos you have received from the hospital or memorial services. Attend a memorial services for your baby or set up your very own memorial service. It can be just you and your partner or you can invite close family and friends.

It might be nice to have a plan to do something nice on the day you experienced the loss or on the original expected due date of your baby. Plan to go to the cemetery where he or she was buried or make a donation to a local charity in his or her name.

## How Differently We Grieve

As a couple, you may notice that your baby's death affects your relationship: sometimes for better, sometimes for worse. As a couple, you may alternate between intimacy and isolation. This may be the first tragedy you've faced together and you may discover new ways of being there for each other. However, the stress of grieving can make you so needy on an individual level that it can be difficult to support each other. Often you will grieve very differently from each other, making it difficult for you to empathize or accept each other's feelings.

Distinct styles of grieving can be attributed to normal variations in personality, socialization, philosophy, coping style, and in the case of women, postpartum hormonal changes. Mothers and fathers also grieve differently because they usually feel different levels of bonding to the baby. There is no right or wrong way to grieve.

Give yourselves permission to have your feelings and give your feelings permission to be different from your partner's. You are entitled to your own feelings. Take responsibility for your reactions. They rise out of your perceptions and your body. No one can "make" you feel a certain way. Instead of blaming your partner for making you feel so angry, crazy, fearful, or sad, see

those feelings as your own reactions, arising out of your own issues. Instead of seeing yourself as a victim, claim creation of your feelings. In doing so, you will also claim the power to face and deal with them. If you can understand where these differences come from, you may feel less threatened by them. Acceptance is also easier if you remember that there are no "right" or "wrong" ways to grieve and that no two people grieve alike. What's important is what is right for you. Feelings are not right or wrong, they just are.

It is important to avoid judging each other. By simply accepting your partner's feelings, you are acknowledging that he or she is entitled to his or her feelings, just as you are entitled to yours. You may not share your partner's feelings and you may not always understand them. You may even feel angry or disappointed at your partner's reactions. But by accepting each other's silences and tears without judging or placing blame, you encourage nonthreatening communication. You also provide the kind of support and understanding necessary to promote healing and to enhance your relationship.

Change will occur in both partners as a result of a baby's death. Many changes that occur can give rise to conflict. Some of the conflicts that might arise:

- Searching for and adopting new philosophies, perspectives, goals, desires, and assumptions about your life, it's meaning, and direction.
- Questioning your religious beliefs and faith.
- Having a new awareness of your needs and emotions; wanting to become more assertive and expressive.
- Dealing with a resurgence of grief from past losses.
- Having varying and different intimacy needs.
- Having varying and different desires for another baby.
- Having disagreements about handling your other children's feelings and behaviors.
- Having disagreements about how much information to share with other people, such as information about difficult decisions, experiences, feelings, and other personal matters.
- Experiencing the end of the "honeymoon period" that existed around the time of death.
- Enduring the stress of grieving for your baby, along with the normal feelings of anger or depression.
- Walking differing paths of grief: you cannot always grieve together or be supportive.
- Harboring negative reactions to your partner's coping style, religious views, or need to dwell on memories and mementos.
- Experiencing differences of how easily each of you adapt to change.
- Having different levels of tolerance for conflicts or distance.

Acknowledging these changes and conflicts can help you weather them together. It may also help you and your partner to openly discuss these matters. Listening without trying to “fix” the other is key. Grieving is a process. Grieving takes time. To grieve is to heal.

The key ingredients to help your relationship survive and grow despite this tragedy include caring about each other, sharing thoughts and feelings, accepting your differences, and reassuring your partner that you are committed to the relationship.

## Suggestions to Aid Relationships

1. Don't expect your partner to be a tower of strength when he or she is also experiencing grief.
2. Be sensitive to your partner's personality style. In general, he or she will approach grief with the same personality habits as they approach life. It may be very private, very open and sharing, or someplace in between.
3. Find a “sympathetic ear” (not necessarily your partner), someone who cares and will listen.
4. Do talk about your child with your partner. If necessary, set up a time period daily where you both know that it is time to talk about your child.
5. Seek the help of a counselor if depression, grief, or problems in your marriage are getting out of hand.
6. Do not overlook or ignore anger triggering situations. It is like adding fuel to a fire and eventually there may be an explosion. Deal with things as they occur.
7. Remember, you loved your partner enough to enter into a relationship. Try to keep your relationship alive: go out for dinner or ice cream, go for a walk, or go on a vacation.
8. Be gentle with yourself and your partner.
9. Join a support group for bereaved parents. Attend as a couple, by yourself, or with a friend. It is a good place to learn about grief and to feel understood. Do not pressure your partner to attend with you if it is not his or her preference.
10. Join a mutually agreeable community betterment program to work side by side.
11. Do not blame yourself or your partner for what you were powerless to prevent. If you blame your partner or personally feel responsible for your child's death, seek immediate counseling for yourself and your relationship.

12. Realize that you are not alone. There are many bereaved parents both locally and nationally.
13. Choose to believe again in the goodness of your life and search for joy and laughter.
14. Recognize your extreme sensitivity and vulnerability and be alert to the tendency to take things personally.
15. Read about grief, especially the books written for bereaved parents.

## Sex and Intimacy After the Loss of a Baby

As couples, you must recognize that grief most probably will have an impact on your sexual relationship for a while, and that this may be totally unrelated to your feelings of love for one another. However, for many couples, sex becomes a tension point. When a couple is drained emotionally and physically, when they feel depressed or angry, or when communication breaks down, sex may be the last thing they desire. For many parents, the link between sex and affection makes them feel hurt by their partner's lack of desire. Mothers must also cope with natural postpartum physical and emotional changes that can make them less responsive.



Sexuality and physical closeness are biological needs that seek balance. As with grief, sexuality after a loss is extremely unique to each person. By coming together sexually after a loss of a baby, a couple may be able to briefly put aside their grieving and feel close to each other, connecting themselves to the flow of life again. It is not uncommon for couples to need tenderness and nurturing more than intercourse initially. Further, some women or men may have an aversion to sex at first because they feel their present agony had its beginning there. Fear of a new pregnancy and by extension, the possibility of another loss can be inhibiting. Sometimes



sex can be used to cover up feelings of grief so the pain doesn't have to be faced. Guilty feelings may also interfere with enjoying one another.

Depression is part of the grief experience. Depression can temporarily cut off feelings of sexual desire. Temporary sexual disturbances in both men and women are normal.

It is important to talk openly with your partner about your feelings and anxieties so that your reactions won't be misinterpreted. Negotiating your sexual relationship requires more nurturing, sharing, acceptance, and reassurance. Be sensitive to your own needs and each others emotional needs during this stressful time. By talking, listening, and holding each other, you can maintain feelings of affection and intimacy without the pressure of intercourse. With patience, mutual tolerance, and understanding, the problems will resolve themselves as healing progresses. Getting away to be alone together may help. If the problems persist far into the second year of grieving, seek professional help.

Grief will change each of you individually, as well as your marriage, and family as a whole. It is not something that needs to be feared, but rather an opportunity to know yourself and each other better. It can be an opportunity to grow.

## Siblings Grief

Talking to your children about the loss of their sibling can be intimidating and overwhelming. As a parent it is often hard to make sense of what you have experienced let alone find the words to explain it to a young child. Some parents are hesitant to even discuss their loss with their children, feeling as though they can just hide it and their children will not pick up on their sadness. The truth is that even if you try to hide your sadness, your child will probably sense your loss, but will not understand what is happening. You may try to reassure them and help them to understand something that you may not fully understand yourself. Where do you start?



### Our need to protect:

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We, as parents, often try to protect our children from traumatic or stressful situations which we feel may be too much for them to handle. However, most professionals agree that one should be open and honest with children about death. Trying to shield them from this may leave them feeling isolated and alone. They may feel unsure of all these new and sometimes confusing feelings they are experiencing. They may interpret this as something they should not discuss; thus leading to unresolved grief. Many times children look back at the time immediately after the death of their brother or sister and feel like they lost their parents too.

If your child has had to deal with grief in the past, such as a pet or grandparent dying, then you can equate the loss of your baby to that experience. If this is their first time experiencing a loss, then you can explain how you are very sad about your baby not being here with you. Explaining that while you are sad now, in time, you will feel better and that death is part of a natural cycle that happens to us all, can be helpful. This also fosters understanding at a young age that death is normal and not something to be afraid of.

### Supporting our loved ones:

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Grief can be so overwhelming that we are sometimes unable to support others who need us, particularly our surviving children. Help your family to heal by talking openly and honestly with your children; and sharing your thoughts and tears. When children are given honest answers to their questions and are allowed to participate in the family grieving process, children handle death and grief as well, if not better, than adults.

Young children often have ideas about death that come from media. Their notions of death are often not realistic. They sometimes believe in magical endings, such as magical causes of death. Children can often internalize issues like this and feel as though they have done something to cause the death of the baby and your sadness. More than anything this experience may make children fear that they will lose you, their parent.

### Answering questions:

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When answering questions, it is all right to say "I don't know." We, as adults, do not always have the answer. Hold your child, tell them that you love them, and reassure them that you will try to find the best way to get through this together as a family.

### Try not to compare yourself or loved ones with others:

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A family who loves together will grieve together. As hard as it is, grief is a natural process. One with different stages, and we need to work through one before we can go on to the next. Grief has no timetable, so be patient

with yourself and your family. Don't compare yourself or your children to others in how you are dealing with your grief. Know that it is important that you are doing it together and with compassion.

#### **Age and personality differences in grieving children:**

Children usually express grief according to their developmental stage and personality, so if you have children in different developmental stages they will express their grief differently. This is why it is important not to compare your children with each other.

Children are occasionally referred to as the "forgotten grievers" because they often appear unaffected by death. Quiet children will need reassurance and support because they will usually appear this way. Outgoing children may ask numerous and repetitive questions about the baby and their death. Children often grieve intensely for short periods of time, play, and grieve again later. Sometimes younger children may have felt jealous of a new baby and wished that it would go away or older children may have felt the pregnancy was inappropriate and therefore resented the baby. These children need to know that these feelings could not have caused or prevented the death of the baby. Expressing this to all children may be important because some children may feel this way and not express it.

#### **Why did our baby die?**

Most children will ask questions over time and they need to know that the baby died because there was something wrong with him/her. If you know the actual cause of death, tell them. Younger children may not know what "death" is and, in this case, you will try to compare it to something in nature such as a flower or a dead animal. It is important not to refer to death as "went to sleep, never will wake up," as this may result in sleep disorders and fear of going to sleep. You should also be careful of saying that "God wanted him/her in heaven" or "they went to heaven because they were so good." Statements like these could lead to resentment and/or fear of God.

Death should not be linked too strongly with illness as it may cause fear the next time the child gets sick. These children need a lot of reassurance that the same will not happen to him. It might be helpful to tell your child that there was something wrong with the baby's heart or lungs.

#### **Dealing with death through play:**

Many times children express their feelings through play. They will play "death" and "funeral." Many times they will draw pictures about what is going on in their life. Some children write stories or keep journals. These can be important keys to what they are thinking and feeling. Check with the library or funeral home in your area for children's books on death. The bereavement

office at Sister's Hospital has a lending library, as does the Western New York Perinatal Bereavement Network. These books can be used to help explain death to small children.

#### **Remembering your baby together:**

Remember that talking with your child can make their feelings seem less frightening. If you've named your baby, refer to him/her by name. In late pregnancy losses, other children may have had the opportunity to hold the baby or there may be pictures of the baby. Those times and pictures can be very helpful in the grief and healing process.

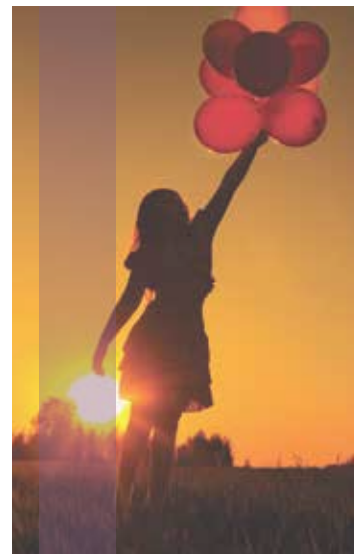
In cases of miscarriage and ectopic pregnancies, the name is probably the memento you have. This may help children to understand that there really was a baby. It is hard, even for adults, to understand something you cannot see. If you have any remembrances of the baby such as pictures, footprints, clothing, etc. you may want to ask your child if they would like to see some of your mementos.

Sitting with them and talking with them about the baby can be a good way of getting them to open up about how they are feeling and what they think about death. This is a good opportunity for you to explain some of your beliefs about death and what happens to us after we die. This will also allow your child to connect and bond with their sibling and feel a part of the process. If your child is resistant to the idea of looking at mementos and does not want to see anything associated with the baby, do not push the issue, but rather, wait until they ask at a later time.

#### **Involving your children:**

Another way to help children through the grieving process is by letting them be involved. If you plan a service, whether it is a wake, funeral, or a memorial service at a church or a funeral home, include your children; they can handle it with your help. Some people choose an informal memorial service such as a tree planting, lantern release, dove release, or balloon release, with immediate family in a location that has special meaning to them. Simple moments like this can have great meaning to a child's experience of the death.

Reading your children stories about babies who have died is a good way for them to understand what has happened and that they are not alone in their experience.





## How Do Children of Different Ages Understand Death?

Each child is unique and matures at his/her own pace, thus will probably not fit neatly under any one category. However, these guidelines may give you an idea of your child's thoughts and behaviors.

### 0 - 6 Months

- No perception of death
- No verbalization skills
- May respond more to parental reaction to loss

### 6 - 18 Months

- Early beginnings of grief
- Perception of death as temporary absence
- Minimal verbalization skills
- May respond to parental reaction to loss
- May respond with confusion
- Common behaviors: clinging, biting, hitting, turning away, regression of speech and other skills

### 18 Months - 5 Years

- Better understanding of permanent state of death, still difficult to understand
- Good verbalization skills
- May respond with confusion or guilt
- May fear for own safety
- May have strong curiosity about death
- Common behaviors: withdrawal, irritability, sleep or appetite disturbances, clinginess, anger/aggression, regressive behaviors (wetting, baby talk), psychosomatic complaints (pains, stomach ache)

### 5 - 8 Years

- Concept of death as a natural process that could happen to them
- Increased use of verbal skills to understand experience
- Increased sense of guilt, egocentricity, and magical thinking
- Common behaviors: suppression of feelings, may become "caretaker", may act out in school or at home

### 8 - 12 Years

- Adult perception of death, may be concerned about own death
- May revert to egocentric or magical thinking
- Understands future
- May be more concerned about mother's health
- Common behaviors: suppression of feelings, aggression, anger, irritability, may victimize other siblings or friends, fearfulness, fatigue, psychosomatic complaints

### Adolescence

- Adult perception of death
- Issues of adolescence may impact reaction
- Confusion, guilt
- May have profound sense of loss due to bonding to sibling on an adult level
- Common behaviors: denial of grief, withdrawal, depression, fear of death, risk taking behaviors (fighting, drugs, defiance, and sexual activity)



# For Grandparents

## Grandparents Coping with Loss

It is often stated that grandparents grieve twice. They grieve for both their grandchild who is gone and for their child who is enduring so much pain.

It is important for you to understand the feelings that grandparents often have after the loss of their grandchild. Grandparents, like parents do not grieve for their grandchild according to the age of the baby but rather by the level of attachment that they had to your pregnancy. Similarly to you, they will grieve for the hopes and dreams of the things they had planned to do with their grandchild, such as birthday parties, special occasions, and sharing hobbies with them. Grandparents sometimes makes plans for their grandchild the same way that parents do. They wonder who the baby will look like and who the baby will act like. It is sometimes hard for grieving parents to recognize and understand how their parents (the grandparents) could be so upset over their loss. You may be so wrapped up in your own grief that you may fail to recognize the pain that your parents are feeling. Parents sometimes feel resentful of their parents for having so much pain over their loss. This is all normal, but if you feel this way please try and remember that your parents love you the same way that you love your baby who has just died. You can understand the need to protect your baby from anything harming him/her and this is often how your parents feel about you. They do not like to see you in pain. They want to take your pain away from you. Sometimes grandparents can be overbearing, trying to do too much in an attempt lessen your pain. The reality is that your heart is broken and it will take time for it to heal.

## The Role of Grandparents

Many grandparents wonder what their role is at this time in your life. Many times they want to take charge and “parent” you because they see that you are in pain. Most grieving parents would agree that a supportive role is the best role at this time for a grandparent. This means that they support you in your decisions regarding how you handle every aspect of your loss. Planning a funeral or memorial service can be an important gift that parents give to their baby. You, the parents, should be able to make all decisions regarding your baby’s final arrangements, burial, cremation, memorial service. Who will be invited, what songs, readings or poems will be included and the location of these events. You, the parents, should make these decisions and then ask for help in any way that you can.

If your parents are not being supportive to you throughout this process, avoid criticizing them, instead try to offer suggestions of what would be helpful to



you. If you are fearful of talking to them about your needs, you could write them a letter to ask for what would be supportive to you. If you call the bereavement coordinator at the hospital where you delivered, they can give you a brochure made specifically for grandparents to help them navigate this process with you. Try to remind your parents that you understand that they want to fix this for you but that there is no “fixing” it and that what you need most is for someone to allow you to just be sad or to cry without judgment.

Sometimes grandparents blame themselves for your baby dying. They may think that their genes or chromosomes may have caused your baby to die. They may run through the same mental checklist that you are trying to figure out what caused your baby’s death.

It is important to keep in mind that every grandparent may not want to see or hold their grandchild because it may be too difficult for them. Your loss might trigger unexpected emotions for some grandparents who may have had a loss years ago. Many grandparents experienced pregnancy loss but it was during a time when society did not allow parents to properly grieve for their baby who died. Mothers were told that it was better if they did not see their baby and that they should forget this happened and move on. If your parent is hesitant to see or hold your baby consider whether or not they may have had a similar experience before you get upset with them. They may seek healing opportunities for their own unresolved grief. Know that by allowing them to help you, even in the simplest of ways, could bring them great comfort. For grandparents who are allowed the opportunity to see and hold their grandchild, it can be a very healing moment and one that will be treasured forever.

Grandparents will go through their own journey of grief and sometimes need someone to journey with them. Please feel free to give them our number if they would also like support at this time.

# Remembering Your Baby

## Remembering and Memorializing Your Baby

This varies from family to family. What you do will depend on your needs, however, we have provided several suggestions:

- Create a baby album with all your keepsakes in it, including your photos. Many people will buy or make a special album just for this purpose.
- Have a remembrance box for all your keepsakes. Many keepsake boxes are homemade, but they can also be purchased.
- Make a collage frame or shadowbox of some of your keepsakes.
- Plant some bulbs or a tree in remembrance of your baby. Let other children participate. It can be very helpful for their grief process.
- Make a donation to one of our Foundations at: [www.FOUNDATIONSofCatholicHealth.org](http://wwwFOUNDATIONSofCatholicHealth.org) or (716) 706-2046.
- Name a star after your baby. For information contact: To Name a Star, International Star Registry at 1-800-282-3333.
- Consider helping others in remembrance of your baby by donating or volunteering with Catholic Health's perinatal loss program, Footprints on the Heart.
- Have a quilt made with pieces of clothing that your baby wore in the hospital or blankets they were wrapped in.



## Living Again

Facing life without your beloved baby can be frightening. Perhaps it seems that your reason for living has vanished. And it is true that your dreams have been shattered. But gradually you will see that, although your life with your baby has ended, a new and different life is waiting to be lived. First, though, you must grieve for as long as you need to grieve. When you are ready to step forward, you may not know what direction to take, and there is no need to hurry. Maybe you will follow several paths as you search for new goals and a new way to experience the world. Whatever you choose to do is fine. Listen to your heart. Keep your mind open. And trust that, at the right time, you will live and love again. The memory of your baby will always be with you as you reinvest in life. His or her life as you knew it has ended, but the love continues to be a presence... forever.

# Resources and Support

## Catholic Health's Bereavement Support

Sisters of Charity Hospital and Mercy Hospital of Buffalo offer bereavement support. It is important to us that you know the support we offer you does not end when you leave your doctor's office or the hospital.

Catholic Health's Footprints on the Heart program helps families cope with the loss of a baby caused by miscarriage, ectopic pregnancy, stillbirth, and newborn death. Grieving has no set time frame and varies from person to person. Take the time that is right for you. We offer different types of support to meet a variety of needs. Support groups and individual counseling sessions are available on an as needed basis. Even if it is months after your loss, feel free to call us for bereavement support when you are ready.

Sisters of Charity Hospital (716) 862-1678

Mercy Hospital of Buffalo (716) 828-2618

## Additional Bereavement Support

### Wings of Love Memorial Fund

Wings of Love is a program of the WNY Perinatal Bereavement Network (WNYPBN) and was started in loving memory of Jacob Wesley Scott and his fellow baby angels. Wings of Love provides financial assistance for burial costs to bereaved parents. Families can qualify for up to \$350 to assist with burial expenses for infants up to one year old. For more information and/or an application, contact Christine Scott at (716) 626-6363.

### WNY Perinatal Bereavement Network

[www.wnypbn.org](http://www.wnypbn.org) • (716) 626-6363

### M.E.N.D – Mommies Enduring Neonatal Death

[www.mend.org](http://www.mend.org)

### Prenatal Partners for Life

[www.prenatalpartnersforlife.com](http://www.prenatalpartnersforlife.com)

### Bereaved Parents of the USA

[www.bereavedparentsusa.org](http://www.bereavedparentsusa.org)

### MISS Foundation

[www.missfoundation.org](http://www.missfoundation.org)

### Centering Corporation

[www.centering.org](http://www.centering.org)

## Remembrance Tattoo

A remembrance tattoo of baby's name or footprint can be a beautiful way to honor your departed loved one.

## Books

- Birth, Breath, and Death: Meditations on Motherhood, Chaplaincy, and Life as a Doula by Amy Wright Glenn
- On Coming Alive: Journaling Through Grief: 100 Prompts to Guide you from Darkness to Light by Lexi Behrndt
- Empty Cradle, Broken Heart by Deborah L. Davis
- Still by Stephanie Paige Cole
- Meaningful Moments: Ritual and Reflection When A Child Dies by Rana Limbo & Kathy Kobler
- Grieving the Child I Never Knew by Kathe Wunnenberg
- Parenthood Lost by Michael R. Berman, M.D.
- Healing After Loss: Daily Meditations for Working Through Grief by Martha Whitmore Hickman
- A Silent Sorrow Pregnancy Loss: Guidance & Support for You & Your Family by Ingrid Kohn & Perry- Lynn Moffitt
- About What Was Lost by Jessica Berger Gross
- Help, Comfort, & Hope: After Losing Your Baby in Pregnancy or the First Year by Hannah Lothrop
- The Invisible Pregnancy Give Birth to Healing by Heidi Faith
- Something Happened by Phyllis Childers
- The Invisible String by Patricia Karst
- We Were Gonna Have a Baby but We Had an Angel Instead by Pat Schweibert

## Keepsakes

### Expressed Impressions

[www.expressedimpressions.com](http://www.expressedimpressions.com)

Photo etching and custom engraving for necklaces, bracelets, key chains, dog tags, and more.

### The Seashore of Remembrance

[www.carlymarieprojectheal.com](http://www.carlymarieprojectheal.com)

Sunset beach remembrance artwork can be customized with your baby's name beautifully written in the sand.

## Cremation Jewelry

Cremation or memorial jewelry is a beautiful way to remember the essence of a departed loved one.

### Close By Me Jewelry

[www.closebymejewelry.com](http://www.closebymejewelry.com)

### 919 Cremation Jewelry

[www.etsy.com/shop/919cremationjewelry](http://www.etsy.com/shop/919cremationjewelry)



**PLEASE COMPLETE FORM AND ENCLOSE FEE - SIGNATURE MUST BE NOTARIZED**

**FEE:** Each copy or Letter of No Record is \$30.00. Make check or money order payable to New York State Department of Health. Do not send cash or stamps. Send to: New York State Department of Health, Vital Records Stillbirth Unit, P.O. Box 2602, Albany, NY 12220-2602.

**NOTE:** If you are not a parent on the Fetal Death Certificate you can only apply if you are a parent or sibling of a listed parent and both parents of the still born are deceased at the time of the stillbirth. You may be asked to provide documentation of the parents' death and of your relationship.

**PLEASE PRINT OR TYPE**

Name of Mother:				
<i>First</i>	<i>Middle</i>	<i>Current Last Name</i>	<i>Birth (Maiden) Last Name</i>	
Residence Address (at time of stillbirth):				
<i>Street Address</i>		<i>City, Town or Village</i>	<i>State</i>	<i>ZIP</i>
Date of Birth of Mother:		Social Security Number of Mother:		
<i>MM / DD / YYYY</i>		<i>Last 4 Digits Only</i>		
Facility:				
<i>Facility Name</i>		<i>Street Address</i>	<i>City, Town or Village</i>	<i>State</i> <i>ZIP</i>
Certifying Physician's Name:		Name of Funeral Director:		
Name and Address of Funeral Home:				
<i>Name of Funeral Home</i>		<i>Street Address</i>	<i>City, Town or Village</i>	<i>State</i> <i>ZIP</i>
Date of Stillbirth:		Date of Disposition:		
<i>MM / DD / YYYY</i>		<i>MM / DD / YYYY</i>		
Name of Still Born:				Check box if a name was not entered on the Fetal Death Certificate: <input type="checkbox"/>
<i>First</i>	<i>Middle</i>	<i>Last</i>		
Name of Father / Parent:				Check box if a name was not entered on the Fetal Death Certificate: <input type="checkbox"/>
<i>First</i>	<i>Middle</i>		<i>Last</i>	
Name of Applicant:				Relationship of Applicant to Still Born:
				Mother/Father <input type="checkbox"/>
				Grandmother/Grandfather <input type="checkbox"/>
				Aunt/Uncle <input type="checkbox"/>
I do swear/affirm that I am the applicant named above and that all of the information provided is true and correct to the best of my knowledge and belief.				
Signed ▶ _____		State of _____ } <b>SS:</b>		
(Applicant)		County of _____ }		
Sworn to Before Me This				
Reserved for use by Notary		_____ Day of _____, _____		
		(Notary Public)		

**NAME AND ADDRESS WHERE RECORD SHOULD BE SENT - NUMBER OF COPIES REQUESTED**

Name: _____		Phone: (     ) _____	
Address: _____			
City: _____	State: _____	ZIP: _____	Number of Copies Requested (\$30.00/copy): _____





Western New York

# Perinatal Bereavement Network

## Authorization Release Form

The hospital where you have delivered is a participating member of the Western New York Perinatal Bereavement Network (WNYPBN), Inc. The mission of this Network is to assist the community to meet the needs of people facing the pain of perinatal death. We promote standards of bereavement intervention through educational support, community programs and referral services.

The WNYPBN has a number of support programs that may be beneficial to you in your time of loss. Please mark any/all of the programs in which you would like to participate, at NO COST to you.

- ☐ The quarterly newsletter called the "Forget-Me-Not," free of charge for one year following your loss. The newsletter is a forum for bereaved parents to share poems and stories, and to memorialize their babies.
- ☐ Information and notifications of up-coming events such as the annual "Walk to Remember," the annual "Evening to Remember" Basket Raffle, holiday services and various Network events.
- ☐ Parent Telephone Support Team (PTST) phone call. A parent with a loss similar to yours will call and speak with you about the many different emotions you may be experiencing.
- ☐ Sibling Program care package for young siblings in grief after the loss of your baby.

Name & Age of Sibling(s): \_\_\_\_\_

- ☐ Funeral Assistance Information / Wings of Love Memorial Fund application and information.
- ☐ I do not wish to participate in any of these programs at this time.

I understand that my records are protected under the Health Insurance Portability and Accountability Act (HIPAA) and cannot be disclosed without my consent. I may revoke this consent at any time by contacting the WNYPBN at 30 S Cayuga Rd - Lower, Williamsville, NY 14221. (716) 626-6363.

I understand that I can forward this information to the WNYPBN, or contact them at any time and they will gladly enroll me in the programs that I request.

Printed Name of Parent: \_\_\_\_\_

Signature of Parent: \_\_\_\_\_ Date: \_\_\_\_\_

Mailing Address: \_\_\_\_\_  
(street) (city) (zip)

Phone Number: \_\_\_\_\_ email address: \_\_\_\_\_

Hospital of Delivery: \_\_\_\_\_ Delivery Date: \_\_\_\_\_

Type of Loss: ☐ Miscarriage ☐ Stillbirth ☐ Early Infant Death ☐ Other: \_\_\_\_\_

Weeks Gestation: \_\_\_\_\_ Baby Sex/Name: \_\_\_\_\_

Witness Name/Signature: \_\_\_\_\_

**>>> HOSPITAL STAFF: PLEASE FAX ASAP TO 716-626-6368 <<<**







## Recognition of Life Request

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Please fill out the information below and a certificate in recognition of your baby's life will be sent to you. The creators of this certificate are bereaved parents themselves, and they hope you will cherish their creation in memory of your precious baby.

Please print the information EXACTLY as you wish it to appear on the certificate.  
Thank you.

Mother's Name: \_\_\_\_\_

Father's Name: \_\_\_\_\_

Baby's Name: \_\_\_\_\_

Honored Date: \_\_\_\_\_

Address where certificate is to be sent: \_\_\_\_\_

Phone Number: \_\_\_\_\_ *(in case of questions)*

---

Please return this form to one of your nurses or if sending from home,  
please mail to the hospital where you were treated:

Sisters of Charity Hospital:

Amy Creamer, LMHC  
Seton Professional Building, Suite 100  
2121 Main Street  
Buffalo, NY 14214

Mercy Hospital of Buffalo:

Jennifer Liberti, RN  
Bereavement Coordinator  
565 Abbott Road  
Buffalo, NY 14220





## Consider Giving...

Gifts made to the Stevens Bereavement Fund, the Nicholas Fund, and the Footprints on the Heart Fund are a living memorial in honor of the loss of beloved babies. All gifts will help support Catholic Health's bereavement programs like Footprints on the Heart, which assists other grieving families during their time of loss. Resources for grieving parents, siblings, and family members as well as bi-annual memorial services are some of the ways in which these funds provide for others in need during their time of loss. All donations are important.

Enclosed is my gift of \$ \_\_\_\_\_ In memory of: \_\_\_\_\_

### THIS GIFT IS FROM:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

### PLEASE NOTIFY THE PERSONS(S) BELOW THAT A GIFT HAS BEEN MADE:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

Please make checks payable to:

Sisters Hospital Foundation  
c/o Stevens Bereavement Fund  
2157 Main Street, Suite 300  
Buffalo, NY 14214  
(716) 862-1990

Mercy Hospital Foundation  
c/o Nicholas Fund  
565 Abbott Road  
Buffalo, NY 14220  
(716) 828-2038

*All gifts are received with gratitude.*



**Many Thanks to Our Donors...**  
all donations are important, no matter how small.



# Just Those Few Weeks

*For those few weeks~  
I had you to myself.  
And that seems too short a time  
To be changed so profoundly.*

*In those few weeks~  
I came to know you...  
And to love you.  
You came to trust me with your life.  
Oh, what a life I had planned for you!*

*Just those few weeks~  
When I lost you,  
I lost a lifetime of hopes, plans,  
dreams, and aspirations...  
A slice of my future simply vanished overnight.*

*Just those few weeks~  
It wasn't enough to convince others  
How special and important you were.  
How odd, a truly unique person has recently died  
And no one is mourning the passing.*

*Just a mere few weeks~  
And no "normal" person would cry all night  
Over a tiny, unfinished baby.  
Or get depressed and withdraw day after endless day.  
No one would, so why am I?*

*You were just those few weeks my little one.  
You darted in and out of my life too quickly.  
But it seems that's all the time you needed  
To make my life so much richer~  
And give me a small glimpse of eternity.*

Susan Erlin





## Catholic Health Bereavement Services

[chsbuffalo.org/footprints](https://chsbuffalo.org/footprints)

### **Sisters of Charity Hospital**

#### **M. Steven Piver, MD Center for Women's Health & Wellness**

Seton Professional Building, Suite 100

2121 Main Street • Buffalo, NY 14214

Bereavement Coordinator:

**Amy Creamer** (716) 862-1678 • [acreamer@chsbuffalo.org](mailto:acreamer@chsbuffalo.org)

mobile phone (716) 346-1013

### **Mercy Hospital of Buffalo**

565 Abbott Road • Buffalo, NY 14220

Bereavement Coordinator:

**Jennifer Liberti** (716) 828-2618 • [jliberti@chsbuffalo.org](mailto:jliberti@chsbuffalo.org)



### **Our Mission**

We are called to reveal the healing love of Jesus to all.

### **Our 2025 Vision**

As your trusted partner, inspired by faith and committed to excellence, we lead the transformation of healthcare and create healthier communities.



[chsbuffalo.org/footprints](https://chsbuffalo.org/footprints)