



YOUR
GUIDE TO
Grief



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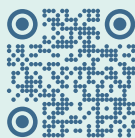
Palliative Care

When an unborn baby is diagnosed with a life-limiting medical condition at any point during pregnancy, it's normal for parents to experience intense grief as well as high levels of anxiety or fear. Palliative care focuses on making the baby as comfortable as possible during their final moments of life, preparing parents and other loved ones for what to expect, and providing support and counseling to help the family cope with their loss.



For more detailed information about palliative care, download this [handout to read or share with others.](#)

Resources



Now I Lay Me Down To Sleep (NILMDTS)

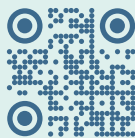
offers parents complimentary photographic portraits to "... aid you in your healing, bring hope to your future, and honor your precious baby." nowilaymedowntosleep.org



The Compassionate Friends offers many types of support to bereaved families dealing with the psychological, emotional, and physical effects of losing a child. compassionatefriends.org



March of Dimes offers a free publication (From Hurt to Healing) to help parents understand and cope with grief after a pregnancy or newborn loss. marchofdimes.org/find-support/topics/miscarriage-loss-and-grief



Share Pregnancy & Infant Loss Support provides a community for anyone who experiences the death of a baby during pregnancy or shortly after birth. nationalshare.org



**Indiana
Department
of
Health**

A photograph of a man and a woman in a domestic setting. The man, with dark curly hair and a beard, is looking off to the right. The woman, with dark hair pulled back, is leaning her head against his shoulder and looking towards the camera with a somber expression. The background is softly blurred, showing a shelf with various decorative items.

Grief is a process
of remembering,
not forgetting.

Author unknown

When a baby dies during pregnancy or shortly after birth, it is a devastating loss for you, your partner, and your entire family. In fact, it may be one of the most difficult experiences you will ever have to face.

Tragically, about 1 in 160 pregnancies end in stillbirth, while about 1 in 300 babies die within the first 28 days of life. Some parents know beforehand that their baby has a life-limiting diagnosis and will not survive. For others, the baby's death during or shortly after birth will be completely unexpected.

When your baby dies, you will need to grieve. You may find yourself grieving not only for the baby, but also for your sense of yourself as a parent and your dreams of giving your baby a long and happy life.

After the initial shock, it's normal to feel a wide range of intense emotions: grief, sadness, anger, confusion, loneliness, and even numbness. Everyone handles grief in their own way and at their own pace. And while you may never really get over your baby's death, it is possible to find your way through your grief and eventually honor your baby's life by moving ahead with your own. The grieving process isn't short, and it isn't easy.

The information in this book reflects the life experience of many parents who have already been through what you are going through now, including:

- Creating early memories with your baby
- Finding your way through the grieving process
- Letting others offer comfort and support
- Looking ahead to hope and healing

You may not be ready for this book yet. But when you are, we hope that what you find here is helpful, hopeful, and comforting. But like so many others before you, you can survive this terrible loss with the help and support of people who care about you.

“No one else will ever know the strength of my love for you. After all, you’re the only one who knows what my heart sounds like from the inside.”

Author unknown



Hello and Goodbye

When you first learn that your baby has died, it's normal to feel a wide range of intense emotions. You may also feel disoriented or have trouble processing what you're being told. For some parents, holding and touching their baby helps them understand that the baby truly did not survive. It also gives them the opportunity to create initial memories of the baby that can last a lifetime.

Spending time with your baby after their death is a difficult—but also important—step in the grieving process. Making this decision is often uncomfortable for parents who were not prepared for the pregnancy to end this way. But many people who did not see or hold their baby also reported feeling incomplete and having an even harder time handling their grief.

MEETING YOUR BABY

To help you through this difficult experience, a nurse will wrap the baby in a blanket and bring them to you. You can then take as much time as you need to say hello and, eventually, goodbye. It is completely up to you who you want in the room with you during this private time.

Spending time with your baby gives you the opportunity to make memories and collect any mementos you may wish to add to a future remembrance book or box. Things you may want to do:

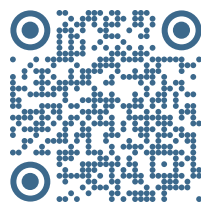
- Name your baby and use their name from now on
- Hold, kiss, cuddle, and speak softly to your baby
- Sing, read, or hold the baby on your chest skin-to-skin
- Request a lock of their hair, handprints, and/or footprints
- Dress your baby or wrap them in a special blanket
- Ask a photographer experienced with infant loss to take photos
- Request a religious ceremony (including baptism) in the hospital
- Collect your baby's clothing, blanket, or hospital bracelet to take home

MAKING DECISIONS

In the first few hours following a baby's death, there will be decisions to be made and things that need to be done. You may have family and friends willing to step in and help while you and your partner focus on taking care of yourselves in this time of extreme sadness.

Designating someone you trust to notify family members, friends, and co-workers about the loss of your baby is an important first step. This person can also let people know whether you want phone calls or visits or if you want to talk about your baby. If you're hospitalized, you can request a room away from other parents and new babies.

You can also ask someone to let your family know if you do or do not want them to remove any baby items from your home. If you're not sure yet, simply ask that the baby's things not be disturbed until you've had more time to think about it.



ADDITIONAL TESTING

You will probably have many questions about what caused your baby's death. The health care team will tell you as much as they can. You can also ask to have an autopsy performed. Not every autopsy will provide definite answers about what caused the baby's death.

But some autopsies are able to find a reason: an illness, disease, or birth defect. Findings from an autopsy can also help clarify certain genetic test results and define any risks for future pregnancies. For further information about autopsies, scan here.

If you decide not to have an autopsy, other tests may be able to give you more information about why your baby died. Ask your baby's health care provider if genetic tests, X-rays, and/or tests on the placenta and umbilical cord can be done. If the cause of your baby's death was a birth defect, a genetic counselor can talk to you about the probability of having another baby with the same birth defect.



FINAL ARRANGEMENTS

Some parents want to remember their baby by holding a memorial, funeral, or other type of religious ceremony. Research has shown that these types of farewell rituals can be an important part of the healing process. They may also help friends and other family members understand the depth of your loss and offer their comfort and support. Whether you choose to have a formal ceremony or not, what's important is that you say goodbye in whatever way is most meaningful to you.

The hospital chaplain can help you locate a mortuary or funeral home if you don't know which one to contact. After deciding about cremation or burial and completing mortuary forms, the funeral home can also help transport your baby and arrange for a viewing. You may also decide against having a viewing or burial. Talk with your family members if that is helpful and never let anyone pressure you into making any of these decisions before you are ready.

Going Home

You can expect your first weeks home from the hospital to be very challenging. You may feel physically and emotionally exhausted and just want to sleep. You may want to be left alone, or you may prefer to be surrounded by family and friends. You may also experience big changes in your normal sleeping and eating patterns.

All of these are normal responses, and there is no need to force yourself to do anything you don't feel like doing just yet. During this time, you may experience a wide range of intense, rapidly changing feelings. On top of this emotional stress, pregnancy and birth have put your body under a great deal of physical stress.

What's important in the first few days home is to get as much rest as possible, pay close attention to how your body is functioning, and make time to give yourself plenty of care and personal attention.

CHANGES AND CHALLENGES

The first 6 weeks after giving birth is called the postpartum period. Even under the best circumstances, handling all the physical, hormonal, and emotional changes that typically happen during these weeks can be challenging. You should also know that some of these changes may be a painful reminder of your baby's death.

Postpartum self-care also includes paying attention to your mental health. Symptoms of anxiety and depression may appear right away or not until months after the baby's death. Your partner may also experience symptoms of depression as you both come to terms with your loss. Treatment is usually effective in relieving these psychological symptoms, and the sooner you seek help, the sooner you can find a treatment that works. Having a strong support network can also help you both get back on your feet.

LETTING OTHERS HELP

The first few days at home are going to be very difficult for you and everyone around you. Grief can make it hard to ask for help or even know what to ask for. But these first days are absolutely the best time to let your friends and family members step in and help while you rest and focus on getting stronger. If someone offers to shop, cook, do laundry, or clean up—say yes. If you have other children and someone wants to take them on an outing—say yes. Then say thanks and go take a nap.

Friends and family members may not always use the “right” words or know how to offer you their sympathy and support. This is especially true if they've never gone through an experience this devastating and painful themselves. If you can, try to remember that they love you, mean well, and are doing their best to offer their comfort and care during this time of grief and sadness.

“She said, How can I help you to say goodbye? It's okay to hurt; it's okay to cry. So come on, let me hold you and I will try. How can I help you to say Goodbye?”

Author unknown





LACTATION SUPPORT

Around the 16th week of pregnancy, your breasts are naturally programmed to start producing breast milk. This process is called “lactation.” Because it is a natural hormonal process, your breasts will continue to make milk after giving birth. You can choose to express your milk to donate or take steps to stop (suppress) your breasts from producing milk.

Before you choose, it may be helpful to talk it over with your health care provider, partner, family members, lactation consultant, and/or social worker.

Breast Milk Expression

Milk you express may be donated in honor of your baby. Even the physical act of expressing your milk to donate gives you some time and space to reflect, grieve, and slowly begin to heal.

Human breast milk can be lifesaving for premature and critically ill infants in NICUs (neonatal intensive care units) whose lactating parent is unable to provide them with enough breast milk of their own. For some parents, donor breast milk can act as a bridge to breastfeeding during early challenges, supporting the baby while the parent works to establish their own milk supply.

To find out more about donating your breast milk to a milk bank, ask your health care provider, a lactation consultant, or a local hospital. For more detailed information or to find a milk bank in your area, you can also visit the Human Milk Banking Association of North America (HMBANA) website at www.hmbana.org.

Lactation Suppression

If you do nothing to remove milk or stimulate your breast, your body will naturally stop producing milk and your supply will dry up. This process, called “lactation suppression,” typically takes about 2 to 3 weeks, although your experience may be different. During the lactation suppression period, you may experience breast swelling, pressure, and discomfort known as engorgement.

If breast engorgement is unbearable, you can release some of the pressure in each breast by hand expressing a small amount of milk. But try to do this sparingly, because the more you drain your breasts, the more milk they will produce and the longer you will be uncomfortable.

Even after your breasts stop producing milk, they may still leak for some time after the discomfort has gone away. To absorb leaked breast milk, use nursing pads or washcloths inside your bra cups.



What can help

- Wear a supportive bra that is not too tight
- Apply cold compresses to reduce swelling
- Keep warm shower water away from your breasts
- Take anti-inflammatory medication
- Use clean, fresh cabbage leaves chilled until crisp
 - o Cover breasts and line bra with cold leaves
 - o Remove leaves when warm and limp

Binding (compressing) your breasts is not recommended and can lead to clogged milk ducts or a breast infection. Never restrict your breasts to make them flatter or wear clothing that is too tight when you're going through lactation suppression.

If you experience difficulty suppressing your milk, contact your health care provider or a lactation consultant.

Grieving Your Baby

It's important to remember that grief is a natural reaction to loss, and over time, you will find a way to manage these feelings. In the early stages, grief may cause you to feel numbness, disbelief, shock, and extreme sadness. Some grieving people may want to scream, cry, yell, or blame someone. It's also common to feel anxious, unable to concentrate, or unable to get out of bed for days. All of these thoughts and feelings are normal expressions of grief. And it will take time to heal emotionally from your loss.

Parents, grandparents, children, and other family members often grieve the death in different ways. Some people are helped by talking about the loss, while others prefer privacy and quiet introspection. Gender and cultural roles may also affect how people grieve, causing some to feel they need to tightly control their emotions, while others need to cry openly.

Simply put, there is no right or wrong way to experience grief. And no one can be expected to feel or express their conflicted and/or changing emotions in the same way as someone else. The best thing you can do is to give yourself and others the time and space each person needs to begin to come to terms with the baby's death.

While you are grieving, you need plenty of comfort and support from friends, family, and others who care about you. Healing takes time, and no one can predict how much time it will take to feel better. What's important is to reach out for support when you need it, be patient with yourself, and allow the grieving process to unfold in its own way and time.

COMFORT AND SUPPORT

Please know that you don't have to go through this terrible time alone. Reaching out to a grief professional or joining a support group to connect with other parents who have also lost their baby can get you the specialized care and support you really need, especially in the first days and weeks.

Grief Counseling

Grief (bereavement) counselors have the specialized training and experience to help you and your family work through the complex emotions related to your baby's death. Whether you go to their office, the counselor meets with you at home, or you meet online or over the phone, grief counseling is a "safe place" for everyone to talk about what happened, how they are feeling, and what happens next.

Expressing your emotions and feelings openly to a trained counselor helps you work through them, instead of turning inward and possibly letting those strong emotions disrupt your life. If you haven't already received it, ask your nurse or hospital social worker for information about recommended grief counselors and other support resources in your area.

Grief is a complicated, evolving human process. Its universality binds sufferers together. More is shared than is different.

Arnold & Gemma



Support Groups

Grieving parents sometimes feel completely alone and disconnected from other people. But it's important to remember that you are not alone. There are thousands of other parents who have lost their own babies, truly understand what you're going through, and want to help and support you.

Peer support groups can provide something you might not find in grief counseling or by trying to handle your grief on your own. When you connect with other parents who have had similar experiences, you never need to explain or defend your feelings. You can expect to be treated with dignity and respect. Healing happens over time as you share your feelings and experiences and learn from the experiences of others.

Some of the organizations listed in the Resources section on page 2 offer in-person groups as well as online connections to other parents and grief professionals. Other sites are more specialized and may only offer online support. Check the websites for the most up-to-date information.

Things to Try

Everyone handles their grief differently. And what benefits one person may not be that helpful to someone else. This list includes activities that other grieving parents have found helpful and may also offer you some comfort and support:



- Ask a close confidant to check in with you daily and be honest about how you're doing
- Write about your experience and feelings in a journal or online memorial site



- Reduce your time on social media to a few minutes each day
- Keep moving your body, even if it's just 10 minutes of stretching or a short walk
- Eat healthy foods (even if you're not hungry) to help your body and mind start to heal

- Rest and sleep; if you can't sleep, talk to your health care provider about your options
- Talk to your employer and ask for as much time away from work as you need



- Be kind to yourself and remember that the baby's death was **not** your fault



- Accept that there are many different ways to grieve and follow your instincts



- Gently correct anyone who may say or do something that is more hurtful than helpful
- If you are having thoughts of hurting yourself, call the National Suicide Prevention Lifeline at **988** immediately

STAGES OF GRIEF

The death of a loved one is very difficult to process, especially when it's a baby. In her 1969 book, *On Death and Dying*, Dr. Elisabeth Kubler-Ross outlined what she saw as the "5 stages of grief" most people go through when dealing with a death or other traumatic loss. The 5 stages reflect the way people try to process change and protect themselves while learning to adapt to a new reality.

Persistent, traumatic grief can cause some people to cycle through the stages of grief very quickly. Other people may take several months (or even years) to reach the final stage. It's also possible to revisit the stages or get stuck in one of them. If this happens, talking with a bereavement counselor or other mental health professional can be very helpful.

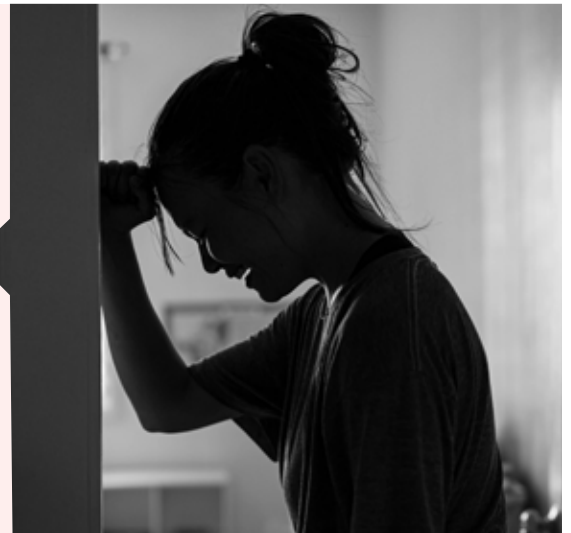


STAGE 1 Denial

Denial helps minimize the pain of your loss by slowing down the process of realizing your baby is really gone. Denying that a death has happened, even though you know it is true, helps you avoid feeling immediately overwhelmed and gives you more time to try to understand what is happening so you can survive the loss.

STAGE 2 Anger

Anger is a common response when grieving people begin to release emotions related to the baby's death. With so many emotional responses happening, you may get angry with friends, family members, health care providers, yourself, or your higher power. Some people find it easier to express their anger than to admit they're scared.



STAGE 3 Bargaining

Bargaining is when you try to influence a different outcome than the baby's death. To try to avoid the intense emotional pain you're feeling, you may ask your higher power or God to intervene or beg to go back in time for another try at preventing the death. Bargaining may actually allow you to begin to feel less helpless.



STAGE 4

Depression

Depression can cause you to feel isolated from other people who want to support you. When reality finally sets in, the loss of the baby feels tragic and unavoidable. You may enter a deeper level of grief than you ever imagined. At this stage, some people will turn inward and become less sociable for a period of time.

STAGE 5

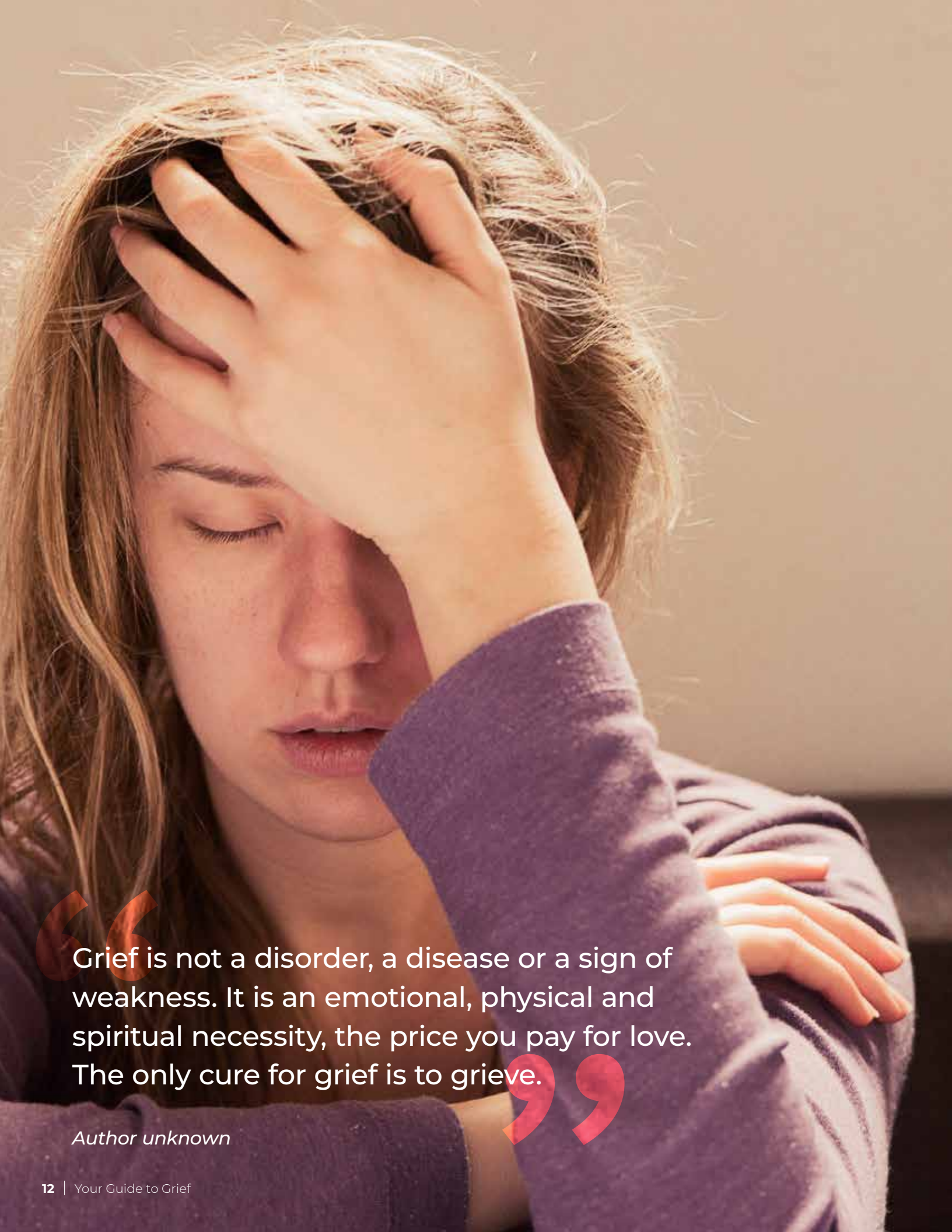
Acceptance

Acceptance comes when you stop resisting the reality of the death and stop trying to change it into something different. At this stage, you accept that the baby is truly gone. You will still feel sad but will be less likely to deny, bargain, or become angry. You may slowly start to reach out to others and want to be a part of their lives again.



Grieving is a necessary passage and a difficult transition to finally letting go of sorrow—it is not a permanent rest stop.

Dodinsky



Grief is not a disorder, a disease or a sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief is to grieve.

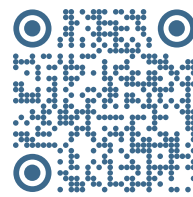
Author unknown

DEPRESSION & ANXIETY

It can sometimes be hard to tell the difference between symptoms of grief and symptoms of depression and/or anxiety. Unlike grief, depression and anxiety are classified as diseases that can be treated, usually with therapy, medication, or some combination.

When the grieving process becomes unbearable or intense or remains unresolved for a long period, someone with no previous history of the disease can develop depression. Others with a history of depression or anxiety may find that their condition worsens significantly when they are also grieving. That's why it's so important to have people in your life who can help you monitor your grief, watch for signs of depression, and help you find medical and/or mental health care if you need it.

Remember that grief is a normal process, but depression is not. If you or a loved one feels that you may have symptoms of depression or anxiety, **please seek help from a licensed counselor or therapist right away about getting mental health support and treatment.**



TALKING TO SIBLINGS

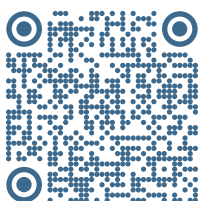
If you have other children (siblings) at home, you know that they pay attention to things happening around them and can often sense when something is wrong. Many experts recommend that parents tell their children about the baby's death and answer their questions simply and truthfully, using words the child can understand.

Try not to use the word "loss" when you're talking to a child about the baby's death, as it implies something that could be found. Children need to understand that death means the baby is no longer alive and will not be coming home to live with the family.

Siblings also need to be reassured that they did not cause the baby's death and are not responsible for their parents and other relatives feeling sad, especially in the first days at home. Using the baby's name and encouraging siblings to talk about their feelings can also be helpful. To understand more about how children grieve, **download this handout** to read or share with others.

GRANDPARENTS

To understand how grandparents grieve for both their child and their lost grandbaby, **download this handout** to read or share with others.



Life After Loss

Because you loved your baby, you will grieve their death. And although grieving a lost loved one is normal, it often feels unbearably painful and confusing. Some days may be especially difficult for grieving parents, including the anniversary of the baby's death, certain holidays, or national celebrations like Mother's Day or Father's Day.

Many parents choose to honor their baby's memory on significant days by planning a remembrance ceremony or taking part in actions that make the world a better place for others. Other parents may prefer to take a day off work, light a candle, and quietly remember a life that ended way too soon.

How you choose to honor your baby is a very personal decision. So follow your heart and remember your baby in a way that feels right to you.



REMEMBRANCE CEREMONIES

Many parents find comfort by holding a remembrance ceremony or celebration of life to honor the baby's passing and preserve their memory. Here are some options:

- Blow giant bubbles into the air and watch them float up toward the sky
- Write a note on "flying wish paper," light it on fire, and watch it burn out in the night sky
- Float flowers in the baby's memory on a pond, lake, or other body of water
- Write the baby's name on a fall leaf and let it float away in a stream or river
- Bring people together to fly kites and joyfully celebrate the baby's memory



ACTS OF KINDNESS

Another way to honor your baby's memory is to donate your energy and resources toward memorial projects (acts of kindness) that can benefit others as well as your own family. Letting siblings help choose and plan a project can help everyone feel closer as a family. Here are some projects to consider:

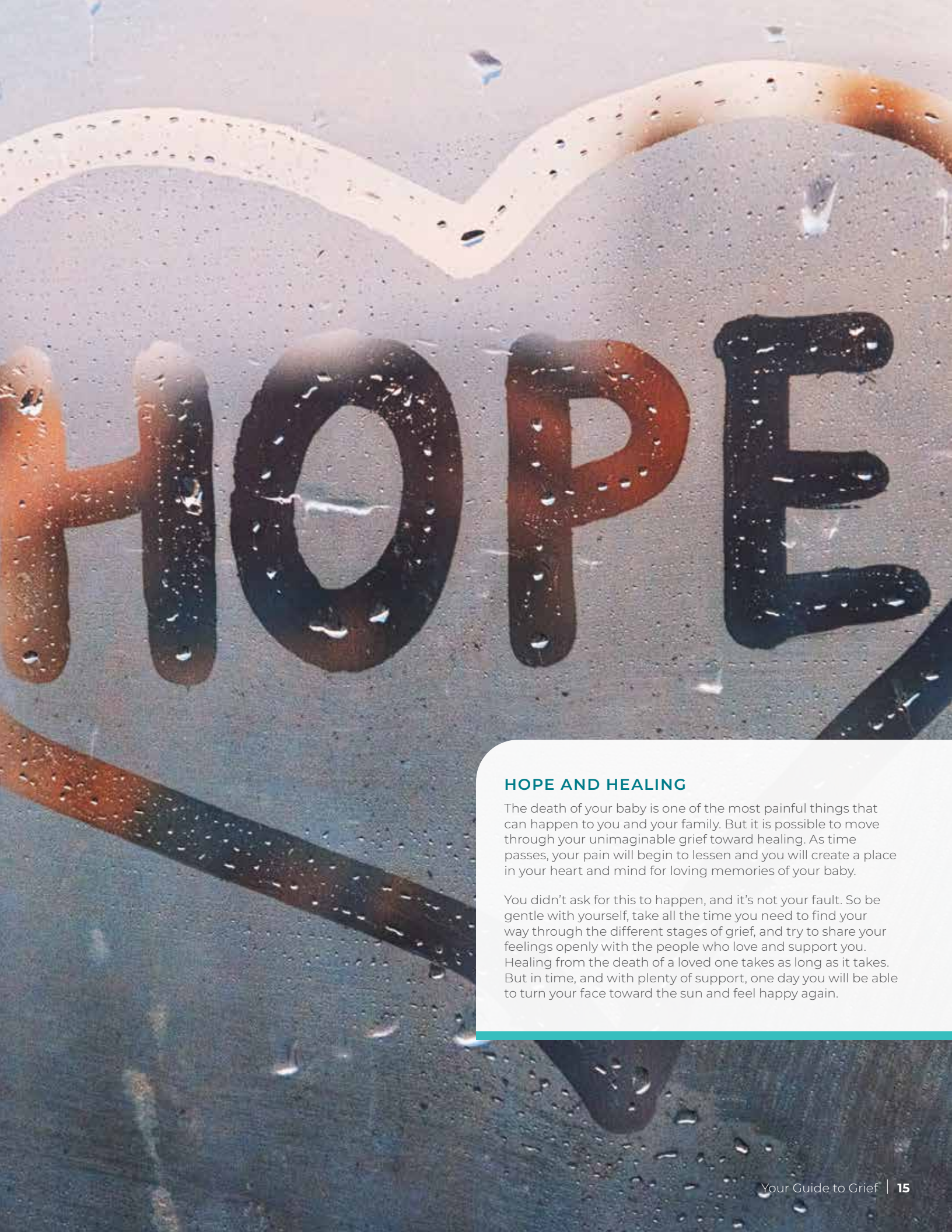
- Create and plant a memorial flower, rock, or vegetable garden in your yard
- Plant a small tree in your yard, on school grounds, or in a nearby park
- Start a charity foundation or make a donation in your baby's memory
- Create a collage or altar in your home with pictures and mementos
- Arrange a butterfly release or donate to a botanical garden's butterfly exhibit
- Paint small stones with your baby's name, symbols, or sayings and scatter them around your yard, neighborhood, in a park, or along a favorite trail
- To help you feel closer to your baby outdoors, build a birdhouse or outdoor bench or hang windchimes on your patio

PREGNANCY AFTER LOSS

After the grief and sorrow of losing one baby, many grieving parents can't even imagine having another child. But as hard as it is to think about now, over time, the hope that a pregnancy brings has the potential to help parents find peace and move forward through their sadness and grief.

Pregnancy following a loss can trigger many intense emotions—from anxiety, grief, and guilt to excitement, relief, and happiness. It may take a lot of emotional support to balance your memories of the baby who died with preparing for the arrival of the new baby. Talking openly about these feelings with your partner, a trusted counselor, and/or other parents who understand your thoughts and feelings can be very helpful.

"Rainbow baby" is a name some people use to describe a healthy baby born to someone who previously had a baby who died during pregnancy or shortly after birth. It derives from the visual of a rainbow appearing in the sky after a storm or other dark, turbulent event.



HOPE AND HEALING

The death of your baby is one of the most painful things that can happen to you and your family. But it is possible to move through your unimaginable grief toward healing. As time passes, your pain will begin to lessen and you will create a place in your heart and mind for loving memories of your baby.

You didn't ask for this to happen, and it's not your fault. So be gentle with yourself, take all the time you need to find your way through the different stages of grief, and try to share your feelings openly with the people who love and support you. Healing from the death of a loved one takes as long as it takes. But in time, and with plenty of support, one day you will be able to turn your face toward the sun and feel happy again.



Grief is like the ocean; it comes on waves ebbing and flowing. Sometimes the water is calm, and sometimes it is overwhelming. All we can do is learn to swim.

Vicki Harrison

Lactation after Loss



After a loss, a mother may have milk come in after 16 weeks gestation. Without some form of milk expression, you may experience breast discomfort.

Please know that you are not alone. We hope this will give you some comfort during this difficult time. You have options when it comes to your breastmilk.

Dry Your Supply

- Only express milk if you feel discomfort
- Apply a cold compress to reduce swelling
- Have good breast support, try a comfortable and supportive sports bra
- Insert washcloths or breast pads in your bra to catch leaking milk
- Reach out to The Milk Bank for help drying your supply

Donate in Honor

- You may choose to donate milk in honor of your baby
- Hand express or use a breast pump to release milk
- The more often you express milk, the more milk you may produce
- This program can connect you directly with The Milk Bank to become a donor

If you have experienced a pregnancy loss and your insurance will not cover a breast pump, please reach out to request one. If you wish to become a donor and have your own breast pump, please email us to start the donor process. You do not need to choose to donate to request a pump or receive lactation support from The Milk Bank.

You may still be eligible for Women, Infants, and Children (WIC) benefits, including lactation support, for up to six months after your delivery. Please reach out with any questions [1-800-522-0874](tel:1-800-522-0874) or find your local WIC clinic at wic.in.gov.

The Milk Bank also offers free lactation support to all moms toll free at 877-829-7470.

Whether you choose to dry your supply or donate your milk, the Milk Bank and the Indiana Department of Health are here to support you!

Fetal Infant Mortality Review

Fetal Infant Mortality Review (FIMR) is a community-based program that reviews stillbirth and infant deaths. The review leads to recommendations that are put in place in the community to prevent future losses. One part of the process is a maternal or family interview, which gives families time to share their story and provide recommendations to improve the situation for others.

The Lactation after Loss program came to light through the maternal interview with two Indiana families. The Poindexter family shared their story about their loss. Scan the QR code below to hear about their experience and how their decision helped inspire this program.

Scan to hear their story



Contact Information

Indiana Department of Health

Email: IDOHFIMR@health.in.gov

WIC: 1-800-522-0874

Email: INWIC@health.in.gov

The Milk Bank

317-536-1670


877-829-7470 (toll free)



Please scan this QR code to find more info on The Milk Bank's bereavement services.

For additional information on Lactation after Loss, please email IDOHFIMR@health.in.gov



A hand is shown holding a broken heart. The heart is split down the middle, and a bright light is shining from the gap. The background is a soft, out-of-focus landscape with green grass and trees, bathed in the warm, golden light of a low sun, creating a hazy, ethereal atmosphere. Large, faint quotation marks are visible in the background, framing the text.

The reality is that you will grieve forever. You will not ‘get over’ the loss of a loved one; you’ll learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again, but you will never be the same. Nor should you be the same nor would you want to.

Elisabeth Kubler-Ross



Indiana
Department
of
Health