

AFE AND INFANT LOSS

We are so incredibly sorry for the loss of your precious baby or babies.

Infant loss is without question, a traumatic experience that will take time to process. It is important to know that you are not alone and that there is a considerable amount of support available through organizations, connecting with other parents who have also experienced infant loss, or attending grief retreats. The roller coaster of emotions following infant loss can be compounded by the traumatic experience of an Amniotic Fluid Embolism. Processing grief, memorializing your baby, learning to accept your new body, grappling with infertility or pregnancy after infant loss are some common experiences following infant loss.

There is no right or wrong way to process your grief. In this pdf you'll find information compiled from others in your same situation. We hope it helps guide and comfort you.

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AMNIOTIC
FLUID
EMBOLISM
FOUNDATION

SPEAKING ABOUT INFANT LOSS

Everyone processes their loss and grief differently and we encourage those who experienced infant loss to seek therapy and find supportive spaces such as infant loss support groups. You may also find support through family and friends; however, your experience can be difficult for others to understand. It is okay to communicate to family and friends that it is too difficult to speak about your experience if you are not ready to share or if you are not receiving the type of support you need.

Finding a space where you feel heard and understood can take time and energy that you may not think you have, but it is an important part of healing. Cultural norms and expectations can also present a barrier to openly discussing your experience and emotions. Emotional isolation can develop if it is difficult to find support, so it is important to keep in mind that you are not alone and your emotions and experiences are valid. Very valid!

The stages of grief are not linear and there is no step-by-step guide on how to speak about infant loss, but having open conversations in a safe and loving space can help you process your experience and deal with the emotions associated with grief.

Check out:

- [AFE Foundation Infant Loss and AFE Support Group](#)
- [Postpartum Support International Pregnancy and Infant Loss Support Group](#)
- [Return to Zero Facilitated Support Groups \(BIPOC and LGBTQ+ offerings\)](#)

MEMORIALIZING

As you continue to process your grief you may find that you would like to do something to memorialize your baby or you may decide that memorializing your baby does not align with your healing process. Remember that everyone grieves and heals differently and you will be supported in your choice.

If you are interested, there are a number of creative ways to memorialize your baby:

- Hold a memorial service
- Send out a Born Still announcement
- Create a memory box with photos, hand prints and footprints, clothing worn by your baby, and other items precious to you and your baby
- Order Custom jewelry or keepsakes with their cremains, fingerprints, or your breast milk
- Order Memorial artwork or sketches (check out Etsy)
- Donate to causes in their honor
- Dedicate a park bench or plant a tree in your baby's honor
- Design and obtain a tattoo
- Create a memory garden
- Pen a journal to your child
- Spend time in a place you frequented while pregnant or where you had thought of taking your baby/child.



We want to honor you and your baby(ies) with a special personalized AFE Memorial candle.

Order here and use coupon code
AFElight at checkout.

One candle per family please.

Even the *smallest of feet* have the power to leave everlasting footprints upon this world.

ACCEPTING YOUR NEW BODY

The loss of your infant coupled with an amniotic fluid embolism will result in changes to your body that can diverge from the expected postpartum changes. It is common to feel a sense of loss of control or loss of autonomy, most especially when many cases of AFE cause you to be unconscious or in a medically induced coma. Experiencing an AFE can have a myriad of effects on the body including, but not limited to: infertility, organ dysfunction, hair loss, weight fluctuation, post-op scarring, etc. AFE Survivors may also experience a loss of intimacy that stem from these changes and the treatments received (e.g. c-section scarring, pelvic floor dysfunction, pain during intercourse, etc.). The time it will take to learn to accept these changes will vary and it is important to work with your healthcare providers, mental health professional, and your partner to process and address these feelings.

VISITS TO THE OBGYN

The **first visit to the OB/GYN** following infant loss and an AFE can be a triggering reminder of your loss and trauma. If possible, try to set aside some time before and after your appointment to engage in activities that help your grieving process. It may also be helpful to limit some triggering questions from clinical staff unfamiliar with your circumstances by utilizing the Patient Clinical Summary. When scheduling your appointments, ask the scheduler to note in your file that you experienced a loss and that you would appreciate the opportunity to avoid unnecessary triggers and a room full of pregnant patients. Consider making appointments for the first or last part of the day.

ANNIVERSARIES

Anniversaries can be a time to honor your baby or may be too painful. Some have found memorializing their baby on anniversaries to be helpful. It is important to know that each year you may feel differently- this is normal and expected.

Reminders of your experience will present themselves in straightforward ways such as holidays, birthdays, anniversaries, birth announcements, etc. It may also present itself in unexpected ways such as smells, sounds, food, clothing, etc. Navigating social media can be especially challenging as people celebrate their pregnancies and babies. As you continue to heal, it is possible to take steps to develop coping strategies for those instances when you are presented with reminders. Working with a mental health provider can help you determine coping mechanisms that work best for you. It can range from taking steps to plan a “reminder kit” for self-care, connecting with your support system, and even allowing yourself to feel your emotions.

PREGNANCY AFTER LOSS

It is normal to consider pregnancy after infant loss and for those feelings to change over time. The decision to become pregnant again is a deeply personal one that will depend on various factors. You may spend time exploring this option with yourself, your partner, social supports, and healthcare professionals. You may also seek peer support and reassurance as needed while allowing yourself the space to continue processing your grief along with feelings of guilt and anxiety that may arise from a new pregnancy.

Check out:

- [Pregnancy After Loss App](#)
- [Sisters in Loss \(BIPOC\)](#)
- [Push for Empowered Birth- Pregnancy After Loss Resources](#)

LACTATION AFTER INFANT LOSS

Reverberations of infant loss include feeling a sense of loss for the dreams and hopes, including plans to breastfeed. Depending on the circumstances, your body may continue to lactate which can result in engorgement and pain. You may choose to speak with your care team to suppress lactation or you may choose to pump for relief until your body slowly stops producing milk. You may also choose to pump to donate milk to others in need.

Check out:

- [Lactation After Loss](#)
- [Le Leche League Lactation After Loss](#)

ORGANIZATIONS SPECIALIZING IN INFANT LOSS

[Return to Zero](#)

[Push for Empowered Birth](#)

[Love Lives On](#)

[The Tears Foundation](#)

[Baby Loss Awareness Week \(U.K\)](#)

VANITA WILLIAMS, CONTRIBUTING AUTHOR

During my 38-week check-up, our midwife tearfully informed my husband and I that a heartbeat was not detected from our precious baby boy. Daniel and I held each other and cried, believing this to be the worst of it. In a daze, we went to the hospital to induce labor and on December 16, 2015, I experienced an amniotic fluid embolism. It was not until my post-hospital follow-up that it truly sunk in how rare and deadly AFE could be.

My AFE also resulted in multiple organ failure which resulted in my need for an organ transplant. As a result, I was medically separated from the Navy and within a few months, I lost my precious baby Isaac, my health, and my career.

I sought solace in those who shared my pain and found that in the AFE Foundation community. Now, as a social worker, I am able to give back and be a source of support for others. My greatest hope is that others can feel a sense of belonging and that this information helps them on their journey.



Stages of Grief

DENIAL

Following a devastating loss, denial and shock is a normal response as we wonder how life as we knew it will continue. Denial can help by pacing our feelings of grief and allow us to cope and process our feelings in a more manageable way.



ANGER

A necessary and often misunderstood part of grieving is anger, which can help us reconnect to the reality of our circumstances. Allowing yourself to feel and release anger will help relieve tension and aid the healing process.



BARGAINING

The belief that we can exchange one set of circumstances for another or wish to undo an event that has occurred. Bargaining forces us to acknowledge that the event occurred as we try to negotiate our circumstances.



DEPRESSION

Depression is a normal, natural response to loss and may intensify as you begin to accept the reality of your loss. Please seek assistance from mental health professionals or social supports when you feel overwhelmed by the intense emotions and physical response following a devastating loss.



ACCEPTANCE

During this stage you may begin to understand the permanence of your loss. Accepting your loss can be painful and is not the same as being alright, 'moving on', or forgetting your loss. You may continue to experience sadness and longing as you accept this new normal and work towards having more good days than bad days.



FINDING MEANING

The stage of grief where you can work towards finding meaning in the love you continue to feel for a person after their death. Finding your individual way to sustain the love you feel following death can help you move forward in your own life.

COMPLICATED GRIEF

The experience of grief varies from one individual to another. The stages of grief are not linear and you may not experience every stage.

It is common to move back and forth between different stages over time and there is no time limit on the grieving process. Lingering symptoms of grief can turn into complicated grief, which feels more intense and can hinder the healing process.

Risk Factors for Complicated Grief

- Loss of a child, spouse, partner, or anyone with whom the person had a very strong and fulfilling relationship
- Negative circumstances surrounding the death
- Financial hardship related to the loss
- History of mood, anxiety disorder or PTSD
- History of trauma or loss
- History of Substance Abuse Disorder or Alcoholism
- Deployed or combat veteran

MANIFESTATIONS OF GRIEF

Physical: Fatigue, Shortness of Breath, Headaches, Sore Muscles, Digestive issues, Sleep disruptions, Trouble concentrating or staying focused, Changes in Appetite, Sleep, and Concentration

Emotional: Denial, Anger, Guilt, Sadness, Yearning, Loneliness, Anxiety, Depression, Numbness

Be the Light

#ENDAFE

Help us BE THE LIGHT for AFE. Your support allows us to continue our research, education, and support initiatives. Together, we can #endafe.

Visit afesupport.org/awareness for more ways you can Be The Light.

- Share Your Story
- Host a Blood Drive (Toolkit icon)
- Use AmazonSmile and designate the AFE Foundation
- Stay Connected Sign up For our Newsletter
- Place Your Pin on the Map
- Enroll Your Case into our Research Registry
- Make a Donation
- Give us a 5 star review (Great Non Profit, Facebook, Google)
- Create a Facebook/Instagram Fundraiser
- Host a Fundraiser/ Awareness Event in Your Community



AFE AWARENESS DAY

March

27

AFE Awareness Day is a day for our community to join together to acknowledge the impact AFE has on families, healthcare providers, and the community at large. We also honor and remember the lives lost to AFE.

WE HOPE THIS GUIDE ILLUMINATES YOUR PATH FORWARD.

If you have any questions or need additional support, please reach out to info@afesupport.org.