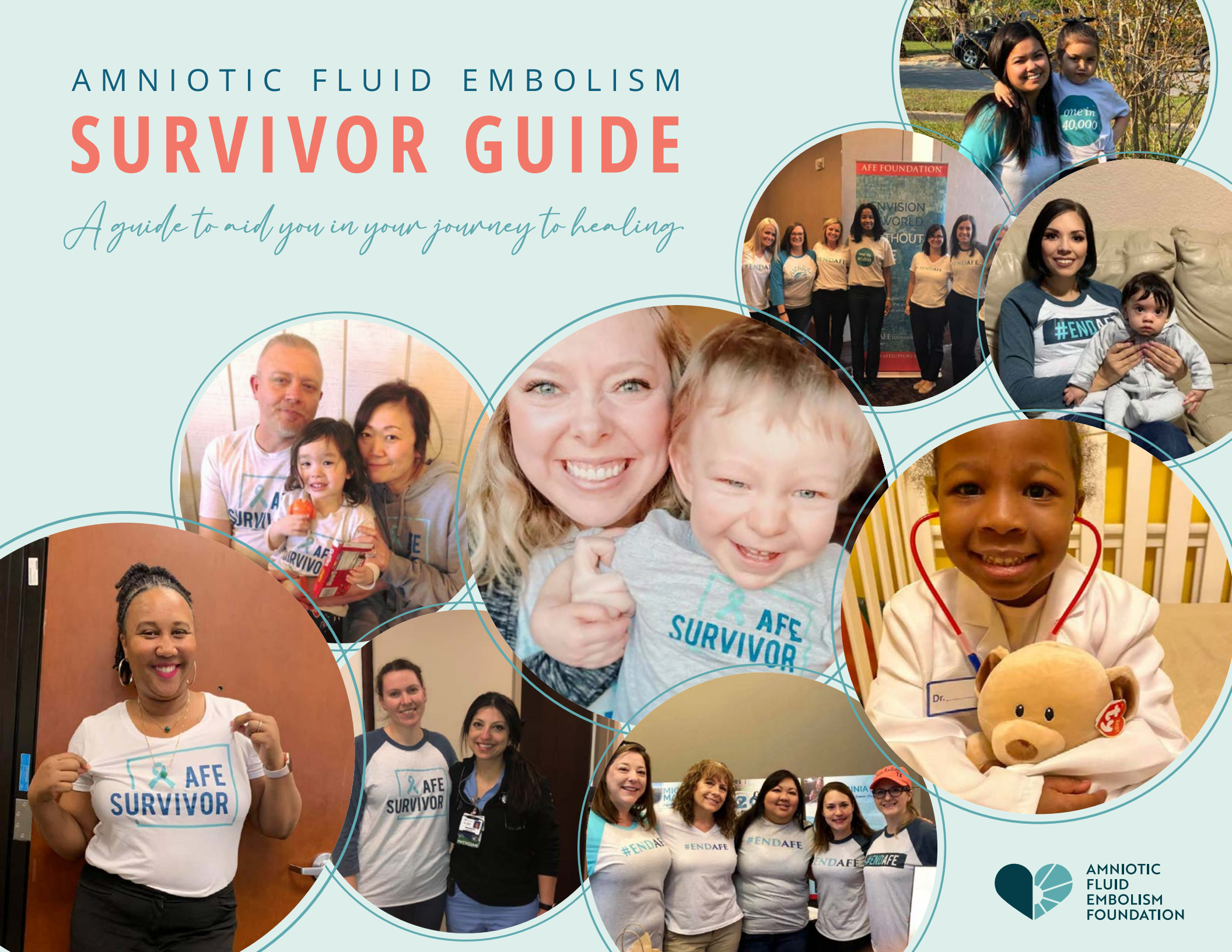


AMNIOTIC FLUID EMBOLISM SURVIVOR GUIDE

A guide to aid you in your journey to healing



AMNIOTIC
FLUID
EMBOLISM
FOUNDATION

Welcome to the AFE Foundation.

We are so glad you found us!

Like you, I am an AFE survivor. I experienced an amniotic fluid embolism during the birth of our son in 2008. During my recovery, I was shocked to find very little information or support for patients and families impacted by AFE. I felt alone and was often overwhelmed with emotion. I was equally surprised to see limited research and little clinician education offered.

The decision to start an organization was easy; the need was too great. A few months after my AFE, I formed the AFE Foundation, a non-profit organization led by affected families and advised by a medical advisory board composed of respected clinicians and expert researchers. Our key initiatives are to support those affected (just like you), promote clinical education, and advance research.

Experiencing an unexpected, rare, and complex birth complication such as an AFE is shocking and isolating. Birth trauma may have lasting physical and emotional impacts. While the challenges faced after surviving an AFE may feel daunting or frightening, know that you are not alone and help is available.

The information in this guide was inspired by the experiences of more than 1,000 AFE survivors and their families. Included are answers to commonly asked questions, helpful self-assessments, and practical tools to aid you in your physical and emotional recovery. While this guide is meant to help, it is not meant to be used as medical advice. We recommend you seek professional guidance with any questions about your specific situation or medical condition.

We commonly refer to our community as a sisterhood and embrace the guiding principle to “be the light.” Welcome sister, may we be a light that helps illuminate your path forward.

Miranda Klassen

Miranda Klassen
Executive Director



ABOUT THE FOUNDATION

The Amniotic Fluid Embolism Foundation is an international network of those affected by AFE, advised by a world-renowned medical advisory board comprising respected healthcare providers and expert researchers.

The organization collaborates with other non-profit organizations, governmental agencies, prestigious academic institutions, and corporate partners to help carry out our mission to advance research, promote education, elevate awareness, and provide support for those impacted.

Since 2008, over 10,000 clinicians across the globe have received direct education through lectures and panels at Grand Rounds, webinars, and medical society meetings.

Our AFE Patient Registry has garnered an international following and collaboration. We have published more than a dozen papers on AFE treatment and management, diagnostic criteria, subsequent pregnancies, risk factors, and how to support patients, family, and staff after a severe maternal event.

More than 1,500 families are engaged in our organization and participate in various support groups, peer outreach programs, and advocacy training opportunities.

Our impact would not be possible without the generosity and engagement of our supporters. While we have much to be proud of, we know there is still a great deal of work to be done.

Together, we can #endAFE!

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BE A LIGHT TO #ENDAFE



AFE SURVIVOR FREQUENTLY ASKED QUESTIONS

Amniotic fluid embolism is a complex medical condition that can be very difficult to understand, most especially because we have such little information about it. Inside you'll find answers to frequently asked questions to help you become more familiar with AFE.

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WHAT IS AN AMNIOTIC FLUID EMBOLISM AND HOW IS IT TREATED?

Although the exact mechanism of how an amniotic fluid embolism (AFE) occurs is not well understood. It is believed to occur when a mother suffers an allergic-like (immune) response to amniotic fluid and fetal material that enters her bloodstream during labor or shortly after delivery. It is important to note that the entrance of amniotic fluid and fetal material into the bloodstream is a normal part of the birth process and in most women, it does not cause this serious reaction.

Most often an AFE involves two very serious and life-threatening complications. These include heart and lung failure (cardiorespiratory collapse) and severe bleeding (disseminated intravascular coagulopathy or DIC). Together, they are exceptionally challenging to treat and require immediate and aggressive medical care.

Heart and lung failure causes breathing problems, irregular heartbeat, seizures, and can lead to cardiac arrest- when the heart stops beating. When the heart stops beating it is no longer able to send oxygenated blood to the body. Lack of oxygen to the body can cause organ failure and brain damage.

Treatment of heart and lung failure includes oxygenating the body by placing a breathing tube (intubation), cardiopulmonary resuscitation (CPR), and medications to help manage blood pressure and help the heart beat regularly.

Bleeding is a normal process of birth. However, in women who experience an AFE, the blood's normal balance (hemostasis) is interrupted by a complicated process causing sudden and excessive bleeding (hemorrhage). This can lead to a condition

known as disseminated intravascular coagulopathy (DIC). DIC causes the over-development of blood clots throughout the bloodstream. This increased clotting quickly depletes the body's platelets and clotting factors that are needed to control bleeding. Excessive bleeding and clotting may lead to more serious complications including stroke, organ failure, and ultimately heart failure.

Treatment of hemorrhage and DIC includes blood transfusions, surgical procedures, and medications to help control bleeding and replenish the body's blood volume.

Advances in critical care medicine offer more complex interventions, although not all hospitals have access to these types of treatments.

EACH YEAR IN THE U.S. THERE ARE **4 million** BIRTHS.

OF THOSE, **50,000** WILL SUFFER A SEVERE MATERNAL EVENT AND...

700 WILL DIE DUE TO BIRTH COMPLICATIONS.

AMNIOTIC FLUID EMBOLISM OCCURS **1** IN
EVERY **40,000** BIRTHS, AFFECTING ABOUT

3,500

WOMEN & FAMILIES WORLDWIDE EACH YEAR.

WHAT CAUSES AN AFE?

The exact cause (etiology) of an amniotic fluid embolism is poorly understood.

Recent research suggests that it is most likely caused by an overreaction of a mother's immune system to substances from the mother and/or baby (amniotic fluid, fetal cells, maternal/fetal antigens) that enter her bloodstream (circulation) during birth, medical procedures, or trauma. It is important to note that these substances often enter the mother's circulation during birth, but most women do not suffer the same reaction.

Older theories suggested it was simply the entrance of amniotic fluid into a mother's bloodstream that caused the reaction. However, research now shows many women are exposed to amniotic fluid in their bloodstream and do not have this same reaction. Another disproven theory was that the amniotic fluid and/or fetal cells obstructed or blocked airflow in the lungs.

Further research is needed to investigate the cause of AFE.

[Learn more about our research initiatives.](#)

WHAT ARE THE SIGNS AND SYMPTOMS OF AN AMNIOTIC FLUID EMBOLISM?

Early signs and symptoms of amniotic fluid embolism develop suddenly and may include:

- Increased anxiety
- An impending sense of doom
- Fetal distress
- Agitation
- Confusion
- Nausea or vomiting
- Chills
- Skin discoloration
- Shortness of breath
- Abnormal vital signs

These may lead to more serious complications including:

- Loss of consciousness
- Seizure
- Heart and lung failure
- Cardiac arrest
- Excessive and uncontrolled bleeding
- Disseminated intravascular coagulation (DIC)
- Stroke
- Acute respiratory distress syndrome
- Brain damage
- Death

WHAT ARE THE RISK FACTORS FOR AN AFE?

Risk factors for an amniotic fluid embolism are extremely difficult to determine. Occurrences of AFE are infrequent and unpredictable making it extremely difficult to study.

Some studies report that AFE may be associated with advanced maternal age, multiple gestation, assisted fertility, placental abnormalities, eclampsia, polyhydramnios, cervical lacerations, uterine rupture, cesarean section, and other operative assisted deliveries.

Currently, there are no known risk factors that would alter the course of standard obstetric practice.

WHEN CAN AN AFE OCCUR?

Amniotic fluid embolisms are rare and a but are a leading cause of maternal death globally.

It can occur during both vaginal and cesarean births. It can occur during any pregnancy. It may occur in the first pregnancy or in subsequent pregnancies after successful previous births.

Although considered to be rare, amniotic fluid embolism can also occur during a D&E (a surgical procedure to fetus, placenta and other tissue), amniocentesis, or trauma (car accident, fall, etc.).

HOW OFTEN DOES AN AFE OCCUR?

Amniotic fluid embolism is rare and a leading cause of maternal death globally.

The statistics around the incidence of amniotic fluid embolism vary because the diagnosis of this syndrome remains one of exclusion and lacks a specific laboratory or imaging test, thus meaning that a diagnosis of amniotic fluid embolism is made after all other reasonable explanations have been ruled out.

Therefore, the incidence of amniotic fluid embolism may be both over-reported and under-reported. Recent publications based on administrative data (data that has not had cases individually reviewed for accuracy) suggests that the estimated incidence of amniotic fluid embolism is 2.5 for every 100,000 births or 1 in 40,000 in the United States and 1 in 53,800 of the approximately in Europe.

For perspective, there are approximately 4 million deliveries in the United States meaning approximately 100 women may suffer an amniotic fluid embolism. There are approximately 700,000 deliveries in the UK each year, meaning approximately 13 women may experience an amniotic fluid embolism.

Amniotic fluid embolism is a
leading cause of maternal mortality
and morbidity worldwide.

HOW IS AN AFE DIAGNOSED?

Amniotic fluid embolism remains a diagnosis of exclusion; meaning all other possible clinical explanations for the symptoms have been ruled out. Unlike cancer or a broken bone, there is no blood test or imaging that can confirm the diagnosis of amniotic fluid embolism.

It may take several days, or in cases when the mother passes months, for a diagnosis to be made. The health care team will review the case usually in a formal debrief and will look at the timing of symptoms and all laboratory tests and imaging to rule out any other possibilities.

In fatal cases, an autopsy is highly recommended and will aid the team in ruling out any other potential causes. It was once believed that an amniotic fluid embolism diagnosis could only be made through autopsy based solely on the presence of fetal material in the lungs or circulation, however, this is no longer a valid diagnostic criterion as many women will have the presence of fetal material in their circulation and not have experienced any of the symptoms of an amniotic fluid embolism.

The AFE Foundation does an amazing job with their *outreach* and *support* of those touched by an amniotic fluid embolism.

They are guided by a true passion to help provide valuable *resources* and *information* regarding this devastating complication during childbirth.

-Michelle M.

WHAT IS THE SURVIVAL RATE FOR A WOMAN WHO EXPERIENCES AN AFE?

Survivability of an amniotic fluid embolism is dependent upon several factors and is therefore very difficult to provide an accurate rate. These factors include:

- Variability of each woman's immune response
- Delivery location (home, birth center, hospital)
- Type of hospital and level of services (critical care, NICU, OB on staff 24/7, blood bank, ECMO capabilities)
- Timing of the event (before or after delivery)
- Immediacy of recognition and aggressive treatment
- Pre-existing health issues or presence of other maternal health conditions (i.e. hypertension, placental abruption, accreta spectrum disorders, etc.)

Published rates from studies are inconsistent and differ depending on how and when the data were collected. Published rates of survivability range from 20-60%.

Although survivability has increased over the last 20 years with advances in critical care and obstetric medicine, it cannot be emphasized enough that an amniotic fluid embolism is extremely difficult to treat and considered one of the most fatal birth complications in the world.

Variations of survival are also dependent on the above listed factors. Some women may make a rapid recovery, while others may suffer a stroke, severe hypoxic brain injury, compartment syndrome, acute respiratory distress syndrome, organ failure, loss of a limb, or other complications commonly found in critically ill patients.

DOES AN AFE IMPACT THE BABY?

Infants who are delivered prior to any symptoms are most often healthy and unlikely to suffer any long-term health challenges related to an amniotic fluid embolism.

Infants who are delivered after a mother begins to exhibit symptoms may be delivered emergently (emergency c-section, forceps, or vacuum) and may have reduced Apgar scores. They are at risk for decreased oxygenation and will require immediate and aggressive critical care interventions.

Infants will almost always be admitted to the neonatal intensive care unit (NICU) which may be for treatment or observation. The survivability of infants is largely dependent on their oxygenation levels at delivery and their response to medical interventions to minimize damage to the brain.

Infants should be monitored for 2-3 years to ensure they meet developmental milestones.

WHAT ARE THE LONG TERM EFFECTS FOR AFE SURVIVORS?

AFE survivors may experience long-term or lifelong complications that range in severity. These complications vary greatly depending on each individual's response to the amniotic fluid embolism and treatments, health history, and genetic predisposition to other illnesses. This list of the most common complications is based on feedback from over 1,000 AFE survivors on their physical and mental health and is not completely exhaustive.

Physical Health

- Mild to severe neurologic impairment
- Memory loss, delayed word recall, and other executive functions such as prioritization, organization, time management, and emotional regulation
- Temporary or permanent heart damage
- Partial or complete hysterectomy
- Complications from stroke (decreased gross and fine motor skills, speech, hearing, vision, and gait)
- Gastrointestinal issues
- Pelvic floor dysfunction
- Nerve pain or neuropathy
- Generalized pain
- Sheehan's syndrome
- Kidney dysfunction requiring dialysis or transplant

Mental Health

Most AFE survivors (and those who are closest to them) are at a greater risk for lasting emotional and psychological effects after their traumatic pregnancy experience.

Feelings of confusion, guilt, isolation, anxiety, depression, and post-traumatic stress symptoms are extremely common. Seeking support and treatment for mental health is a very important aspect of the overall recovery process.

It is recommended that all survivors and their close family consult with their health care team to regularly address both their physical and mental health. Be sure to read our expansive survivor guide with more information and resources about mental health.

CAN LABOR INDUCTION CAUSE AN AFE?

There has been a great deal of interest in the issue of induction as a potential risk factor for amniotic fluid embolism. Research on the relationship between AFE and induction is inconclusive and confusing.

The origin and intent of induction are meant to help save lives, not compromise a mother or baby's health, or worse, cause death.

Induction of labor has become a widely adopted practice in modern-day labor and delivery. However, induction is often a highly debated topic as there are benefits as well as risks.

The AFE Foundation looks to the organizations that have the most current and accurate information on induction, such as the Society for Maternal-Fetal Medicine (SMFM), American Congress of Obstetricians and Gynecologists (ACOG), Association of Women's Health and Neonatal Nurses (AWHONN) and the California Maternal Quality Care Collaborative (CMQCC).

Some medications used in labor induction will list amniotic fluid embolism as a potential risk. These medications are commonplace but used as off-label drugs, meaning they were developed for other medical conditions. When off-label medications are used, it means during drug development no studies looked at the use of these medications for labor induction.

Drug manufacturers often include a comprehensive list of potential complications when their drug is used for off-label purposes to remove any potential liability on the drug manufacturer.

Induction of labor may result in a uterine rupture which has been listed as a contributing factor for amniotic fluid embolism in some studies.

Until more conclusive research is completed, the AFE Foundation is reluctant to take a position on the relationship between induction and the occurrence of amniotic fluid embolism.

The decision to induce labor should be made solely on an individual case basis when all information is presented and the risks and benefits to both mother and baby are clearly understood and consented to.

CAN I PHYSICALLY HAVE ANOTHER CHILD AFTER AN AFE?

Research on pregnancy following amniotic fluid embolism is very limited. The National Institutes of Health released a comprehensive review of amniotic fluid embolism in 2009 and at that time there were nine cases of successful subsequent pregnancies following AFE with no instances of recurrence.

In November of 2015, [a publication from our patient registry](#) reported 26 out of 80 women who were diagnosed or presumed to have suffered an amniotic fluid embolism had subsequently conceived with no reported recurrence.

The experience of an amniotic fluid embolism is a traumatic experience for the mother, spouse/partner, existing children, extended family, friends, and even the healthcare team. Deciding whether to become pregnant again can be a very difficult decision.

We advise all women considering a subsequent pregnancy to seek a pre-pregnancy consultation with a [maternal-fetal medicine doctor](#) (often referred to as a perinatologist) who specializes in high-risk obstetrics. A perinatologist can review your medical history and provide you with an informed and personalized perspective.

Sometimes a doctor will advise against a future pregnancy because they are unfamiliar with amniotic fluid embolism or may have their own fear and trepidation in being your physician. A well-meaning obstetrician or perinatologist may not have the

experience to provide you with sufficient advice. Or, they may have strong evidence that a subsequent delivery puts you in a very high-risk category.

We advise seeking consultation with at least a few obstetricians or maternal fetal medicine specialists to ensure you have the information you need to help make a decision and feel confident. Ultimately, it is a very personal and individualized decision to make. Having the right healthcare team and support from your spouse/partner and extended family and friends will allow you to feel confident in your decision.

We also strongly recommend seeking professional counseling from [a trained and licensed birth trauma professional](#) to aid in the mental health surrounding this decision.

If you would like to connect with others who have gone on to have subsequent pregnancies, please join our support group for those interested or who have successfully had a subsequent pregnancy. It is important to note that this group is merely for support and should not be viewed as medical information or treatment advice.

There is currently no standard of care or protocol for subsequent deliveries of amniotic fluid embolism survivors. Each case is unique and should be treated as such.

WHAT CAN I DO TO HELP PREVENT AN AFE?

Although having been recognized since the 1920s, amniotic fluid embolism remains poorly understood. Without a clear idea of what causes an amniotic fluid embolism and no ability to predict a woman's susceptibility means there is no way to prevent it from occurring.

However, we know a woman's greatest chance of survival is to deliver at a hospital with the ability to provide rapid and aggressive treatment. Increasing awareness among the medical community allows for more prompt recognition and treatment, leading to improved outcomes for mothers and infants.

Additionally, research is crucial to aid in our understanding of this enigmatic complication. Research is needed to identify causes, preventative measures, and effective treatments. The Foundation is working hard to advance research, promote education, and elevate awareness. To contribute to the AFE Foundation's efforts, please consider making a [donation](#) or [getting involved](#).

An AFE can have a tremendous impact on all who are involved. This can include the patient, spouse/partner, family members, friends, and healthcare providers. To meet the unique needs of each person affected we have established several Facebook support groups to help foster community and share resources.

Please visit our website for specific guides and resources. Also, consider joining one of our many support groups.

- GRIEVING FAMILIES
- GRIEVING FRIENDS
- AFE WIDOWERS
- AFE SURVIVORS
- AFE SURVIVORS WITH INFANT LOSS
- AFE SURVIVORS WITH SIGNIFICANT BRAIN INJURY
- FAMILY MEMBERS, FRIENDS, AND HEALTHCARE PROVIDERS

UNDERSTANDING WHAT PHYSICALLY HAPPENED TO YOU

An important step in the healing process is to better understand what physically happened to you. Many who experience an AFE have limited or no memory of the event and are challenged to piece together what happened. This can lead to confusion about your physical health and your ability to advocate for future health care needs. Many survivors have shared their frustration of having to rely on their spouse/partner or family members to help explain what happened to them. Oftentimes, those same individuals are also triggered from such a traumatic event that they may want to avoid the topic, don't remember all of the specifics or may be fearful to tell you such difficult memories.

There are a few ways you can learn more about what happened to you:

- Request a copy of your medical records.
- Ask for a consultation with the medical provider who saw you for your prenatal care or the medical provider who cared for you during your AFE.
- You may also contact the hospital labor and delivery unit and ask for the chair of the department to inquire about a patient debrief to go over your case.
- Utilize our AFE Survivor Clinical Summary

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“Waking up in the hospital, I could not possibly understand what the doctors were saying happened to me and my daughter. My family immediately found the AFE Foundation online.

We were able to *educate ourselves* and find *support*, and understand we were *not alone*. I'm not sure where I would have been without the foundation in my recovery process and I find great solace staying involved with the organization.”

EMILY S., AFE SURVIVOR



REQUESTING AND READING YOUR MEDICAL RECORDS

Reading your medical records can assist you with better understanding what happened and may aid in your follow up health care. Below addresses the most common questions about how to obtain and read your medical records.

When should I request my medical records?

We recommend it as soon as possible.

How long will hospitals keep my medical records?

Hospitals are only required to keep records for a specific amount of time. Most often it is between 5-10 years, although the requirements differ from state to state, or country.

How do I request my medical records?

To obtain your records you must complete a Release of Health Information form from your specific hospital(s). The form is usually available on the hospital's website under "patient" or "medical records". You may also call the main hospital phone number and ask to be connected with the medical records department. Once you complete the form you can send it back by mail, email, or fax. If you were transferred from one hospital to another, you will need to request records from each separate hospital. Also, some hospitals outsource their medical records to an outside company that specializes in document storage. If that is the case, you will deal directly with the vendor rather than the hospital.

Should I get a full copy of my medical records?

You usually have the option to get a full copy or a summary copy of your hospital stay. A summary copy is usually sufficient in assisting you with understanding the over course of your care. Summary copies typically include doctors and nurses notes, operative reports, consult notes, health history, test results, and the discharge summary. A summary copy significantly reduces the total number of pages of your records.

In some cases, you may want to have a full and complete set of records. Full records usually include lab values, blood transfusions records, medications, measurements of fluids, and heart rate strips.

Is there a cost to getting my medical records?

Most hospitals or record storage companies will charge a fee. It can be a flat fee or per page. Flat fee charges may differ depending on how the records are sent to you. Usually, email is the least expensive. However, you may have too many pages of records for them to be emailed. Hospitals typically do not charge if the records are being requested for "continuity or follow up care" by another physician. You may ask your obstetrician, midwife, or primary care physician to request a copy and ask them to give it to you. Or, you may negotiate fees with the hospital or medical records servicer.

Where should I store my medical records?

Paper records should be stored in a box or binder for future reference. Electronic records should be stored on a thumb drive or separate hard drive. We recommend storing electronic copies in 2 places to protect against accidental deletion.

Where should I start when reading my medical records?

One of the best ways to begin to read your records is to organize them by grouping them into categories such as progress notes, operative reports, lab results, imaging reports, etc. Then, put those groupings into date order.

We recommend reading the progress notes and operative reports first. If you received cardiopulmonary resuscitation (CPR) there will likely be a “code blue record” or “code blue sheet” or sometimes the information may be included in the anesthesia record.

What if I don't understand what my medical records say?

Understanding medical language and terminology can be challenging. Medical records are meant for healthcare providers to be able to document the care you received and are intended to be used by other health care providers. Looking up medical terms is an easy and effective way to learn a little more about the condition, procedure or medications that were used. Consider enlisting the help of a family member or friend who may be in the medical field. Or, you may also ask your primary care physician or OBGYN for help in better understanding specific sections of your record. You may also request help from the AFE Foundation. Send us a message and we will find a mentor to assist you in reading your records.

Will reading my records trigger an emotional response?

There is a very strong likelihood that reading your medical records and revisiting such a difficult and frightening moment in your life will bring a great deal of emotion and potentially symptoms of anxiety and/ or PTSD.

It is okay to request your records and not read them until you feel you are ready to do so. If and when you do plan to read them, we recommend that you establish a time frame for when you plan to read them and for how long. Depending on how many records you have, it may take several hours or days to read them in their entirety. Setting boundaries and being cognizant of the time it will take and how you may feel afterwards are important considerations.

Be sure to let your spouse/partner or close family member know you are taking time to read them. Be aware that if your spouse/partner who was with you during your AFE does not show interest in reading your records with you, it is likely a sign that they are wary of revisiting those difficult memories. Be sure to ask those who were with you if they are open to answering questions you may have and when is a good time to ask them.

We recommend that you do not read them late into the evening as it may trigger sleep disruptions. We also encourage you to practice self-care after reading them. If you find that reading them triggers you too much, put them away. Consider seeking therapy to learn helpful tools to help you process emotions and triggers.

AFE SURVIVOR CLINICAL SUMMARY

Have important clinical details of your care all in one place!

Our [AFE Survivor Clinical Summary](#) is a two-page editable PDF document designed to summarize the most significant aspects of your clinical care to better assist you in understanding what happened to your body.

You can ask your OBGYN, Midwife, or other primary healthcare provider to help you complete it. While they may not have some of the details in their charts, most can access your medical records and complete a good portion of the form. If they are unable to assist with that request, you may also use this as a guide when reviewing your medical records.

The summary form also serves as a great way to inform other healthcare providers in the continuity of your care such as follow up visits with specialists or mental health providers. It aims to minimize the triggers associated with retelling the event and gives healthcare providers a quick and simple format to get up to speed on what you experienced.

Simply provide it to them at your follow up appointment or email/fax/mail to them prior to your appointment.



EMOTIONAL IMPACT AND LEARNING TO COPE

Many amniotic fluid embolism survivors, their spouses, and family members report experiencing feeling traumatized or report mental health challenges and perinatal mood and anxiety disorders (PMADs) as a result of the AFE. In this section we explain more about the impact of birth trauma and offer resources and self assessments to help you discern if you may be experiencing a perinatal mood and anxiety disorder. Our Let's Talk Therapy section will assist you in learning the various types of support professionals, common forms of therapy, and how to find one that is right for you.

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BOOK RECOMMENDATIONS



COMMON CHALLENGES YOU MAY FACE AFTER AN AFE

brain fog

accepting your new body

conflicting feelings
(ex. grief, gratitude)

seeing pregnant women

fertility

returning to the workplace

survivor's guilt

struggle with anniversaries

going to medical appointments

relationships after birth trauma

birth & pregnancy announcements

physical pain

worry of your baby's health

breast feeding

managing new medications

managing the home

intimacy

mental health and anxiety

delayed bonding

struggle with birthdays

triggers in a health care setting


BIRTH TRAUMA

Birth Trauma is experienced by a majority of women who survive an AFE. Trauma is an emotional response to a life-threatening or frightening event. Birth trauma is distress experienced by a mother during or after childbirth and may be caused when the mother or baby's life is threatened. It may also be caused by an extreme sense of powerlessness, isolation, lack of care, fear, or anxiety. Birth trauma is especially complex because birth is often expected to be a happy and celebratory event in one's life. Click here to learn more about birth trauma.


The postpartum period following an AFE may be accompanied by confusion and disappointment. Your birthing expectations were shattered and you've been left to make sense of it all. Your emotional and physical recovery from an AFE may also be further complicated by perinatal mood and anxiety disorders (PMADs).



HELP IS AVAILABLE IF YOU WANT TO TALK

 **National Suicide Prevention**
1-800-273-8255

 **Suicide Prevention Hotline**
1-800-SUICIDE

 **National Postpartum Depression Warmline**
1-800-PPD-MOMS

Postpartum Support International also has specialized support coordinators. Find them [here](#).



UP TO

45%

OF NEW MOTHERS
HAVE REPORTED
EXPERIENCING BIRTH
TRAUMA.

Emotional healing CAN BE DIFFICULT
WHEN NEEDING TO TAKE CARE OF
AN INFANT OR PROCESS GRIEF.



THE *whole family* MAY BE IMPACTED
(SPOUSE, FAMILY, CHILDREN).

A MAJORITY OF THOSE WHO
EXPERIENCE PTSD AFTER BIRTH
will recover.



PERINATAL MOOD + ANXIETY DISORDERS

A large number of women in our community report experiencing perinatal mood and anxiety disorders. These disorders include postpartum depression, postpartum anxiety, obsessive compulsive disorder, postpartum psychosis, and post traumatic stress disorder.

Perinatal Mood and Anxiety Disorders are *not your fault* and *not who you are as a mom*. They are a *temporary medical condition* and are *treatable*.

POSTPARTUM DEPRESSION

Postpartum depression (PPD) occurs after childbirth and is comparable to depression unrelated to child bearing. The main difference is that PPD disrupts your postpartum experience, just as your AFE disrupted your birthing experience. It can devastate your expectations of parenthood and leave you feeling like you weren't meant to do this. But, here's the good news, it's highly treatable.

Sometimes it can be difficult to discern postpartum depression from the "baby blues". The baby blues occur shortly after birth due to the fluctuation in hormone levels.

Below is a quick side by side to help you identify what you may be feeling and if it might be PPD.*

Think you may have Postpartum Depression?

The risk assessment below can help you understand if you might be experiencing symptoms of PPD. This is not a diagnostic tool, but may be helpful in assessing your symptoms. If you believe you are suffering from symptoms of PPD, it's important to seek professional support.

TAKE THE PPD RISK ASSESSMENT

Want to learn more about PPD?

- [March of Dimes](#)
- [Women's Health.Gov](#)
- [Mayo Clinic](#)
- [NIH](#)

FEELING BLUE OR IS IT SOMETHING MORE?

Baby Blues	Postpartum Depression
Very common	1 in 7 women will develop PPD
Onset typically begins 3-5 days after delivery due to hormone fluctuation and other physiologic changes that accompany birth.	Feelings persist beyond 3 weeks after birth and can last many months if not treated
Usually resolves within 3-4 weeks as hormones stabilize	Requires treatment, most commonly with therapy and/or medications
Crying	Excessive crying
Mood swings	Intense mood swings, feelings of anger, and sadness
Anxiety	Extreme anxiety Lack of interest in regular activities
Feeling overwhelmed	Feeling withdrawn from family and friends
Exhaustion	Sleep disturbances such as insomnia or sleeping too much
Having a hard time concentrating	Feeling worthless or not being a good parent
	Inability to bond with your baby Thoughts of harming your baby or yourself

Be sure to check out our



WOMEN OF COLOR AND POSTPARTUM DEPRESSION / PMADS

We acknowledge and celebrate that our community is diverse in experiences, cultures, and geographic locations. It is our priority to ensure that every member of our community gets the support and help they need to not only survive but thrive.

Therefore, it is deeply concerning to us that AFE survivors of color may be at an even increased risk for postpartum depression. [The National Alliance on Mental Illness](#) shares that although PPD can affect all mothers, much of the research conducted and screening tools developed have been focused on white women. As a result, doctors may miss [somatic symptoms](#) that tend to present in nonwhite women, such as high blood pressure or unexplained body aches, pain and nausea and further placing [women of color at increased risk](#) for PPD.

Nurse Ashley Kilgoe, shares from her personal lived experience and research she has conducted that “many Black women experiencing PPD are silenced by shame and stigma. In the Black community, seeking help is often viewed as a sign of weakness. Additionally, when someone makes the decision to seek guidance, they are likely to turn to family, friends or religious leaders rather than trained personnel. In the U.S., when it comes to mental illness, Black individuals are less likely to receive treatment than nearly all other racial and ethnic groups.”

Reasons many do not seek professional help can include:

- Stigma and perceptions of mental illness in the Black community
- Experience with inaccurate diagnoses
- Lack of representation or diversity in health care
- Distrust of the healthcare system
- Perceived racial discrimination

To address these potential roadblocks in seeking treatment we have listed the following resources below and throughout this guide.

- providers.therapyforblackgirls.com
- melanineandmentalhealth.com/directory/therapists
- blacktherapistsrock.com

Our colleagues at the [Shades of Blue Project](#), an organization dedicated to helping minority women with PPD, offer several online support groups and [community based programs](#) to meet the unique needs of Women of Color suffering from PPD.

If you need any assistance in finding the right support, please don't hesitate to [contact us](#).

KAY MATTHEWS, FOUNDER OF THE SHADES OF BLUE PROJECT

“If all women receive the same quality of care, then there would be no need to have specific care for black women in the future. **Acknowledgment, respect, and support** are the three things that must be present in our care treatment because without it we continue to experience racism and lack of care every time we go into clinics and hospitals seeking treatment.”



POST-TRAUMATIC STRESS DISORDER

AFE survivors and their partners may develop post-traumatic stress disorder or PTSD. PTSD is a serious condition that can occur after a person has experienced or witnessed a traumatic or scary event where there was serious physical harm or threat of physical harm or death. A diagnosis is made by a mental health professional and requires treatment. Read more about the link between traumatic birth and PTSD [here](#).

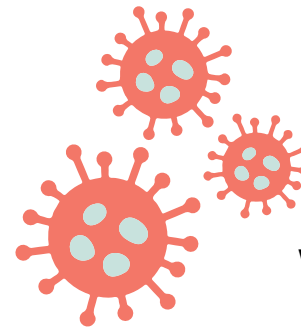
Concerned you may have PTSD?

The risk assessment below can help you understand if you might be experiencing symptoms of PTSD. This is not a diagnostic tool, but may be helpful in assessing your symptoms. If you believe you are suffering from symptoms of PTSD, it's important to seek professional support.

TAKE THE PTSD RISK ASSESSMENT

POSTPARTUM ANXIETY

Postpartum Anxiety (PPA) affects up to 10% of postpartum women. Symptoms may include constant worry, hypervigilance, racing thoughts, sleep disturbance, appetite changes, and a feeling that something bad is going to happen. PPA can also include obsessive thoughts or be closely related to postpartum obsessive compulsive disorder. Learn more about [PPA](#).



COVID-19 has added to the trauma of surviving an AFE, increasing feelings of isolation and limiting access to support, which may lead to an *increased risk* of **PPD** and **PTSD**.

POSTPARTUM OBSESSIVE COMPULSIVE DISORDER

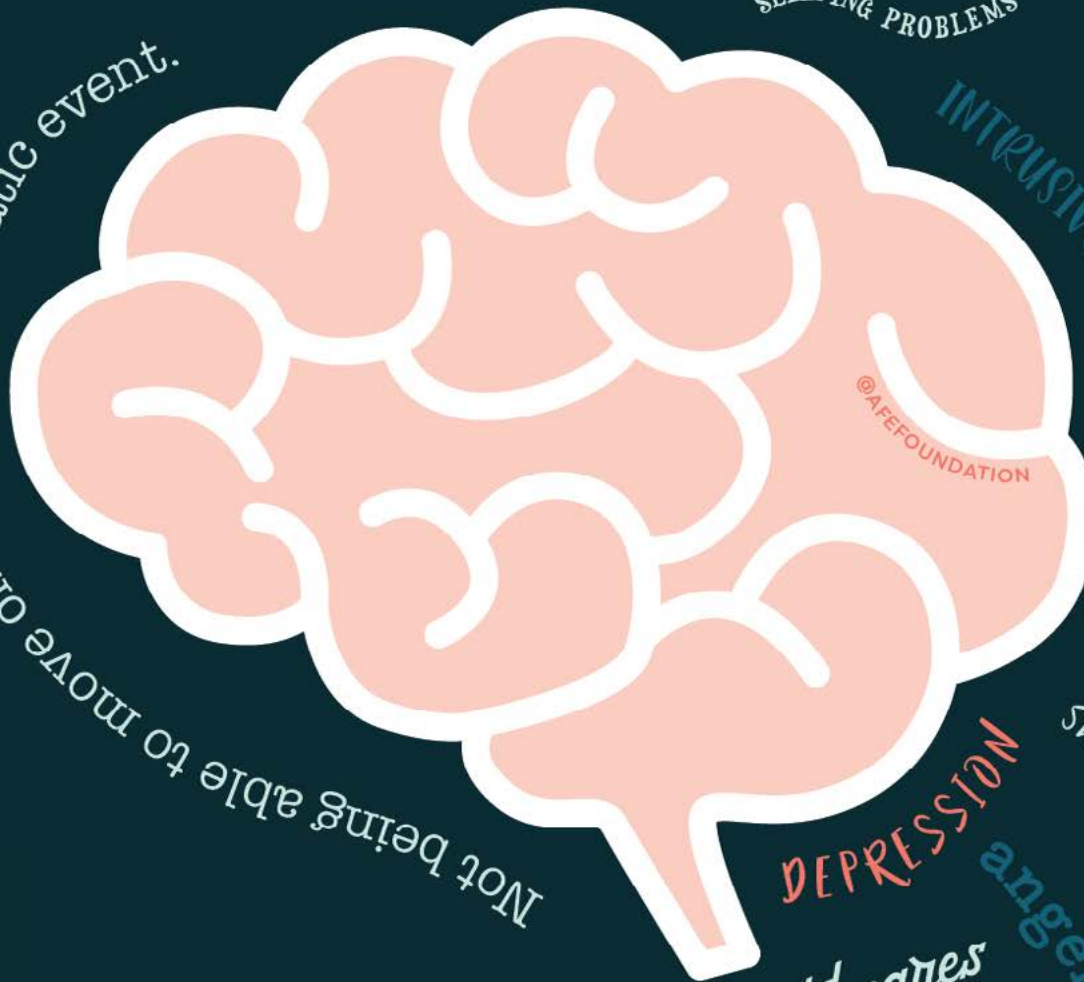
Postpartum obsessive compulsive disorder affects between 3-5% of postpartum women and typically includes obsessions and/or compulsions.

- Obsessions are often centered around the newborn. These are persistent, repetitive thoughts that can be very upsetting, such as images of harming the baby.
- Compulsions occur as a way for the mother to reduce their fears or obsessions. These compulsions may be checking, counting, cleaning or thought based.
- Mothers with Postpartum OCD understand that their thoughts are strange and they are unlikely to act on them.

Without treatment, Postpartum OCD is likely to worsen over time. The good news is that treatments such as Cognitive Behavior Therapy and Exposure Response Prevention, along with medication, have shown great success in treating Postpartum OCD. Click [here](#) for more information on Postpartum OCD.

WHAT PEOPLE THINK PTSD IS vs WHAT PTSD ACTUALLY IS

Not being able to move on after a traumatic event.



AMNIOTIC
FLUID
EMBOLISM
FOUNDATION

POSTPARTUM PSYCHOSIS

Postpartum psychosis is rare, occurring in just .1-.2% of postpartum women. It typically occurs within the first 2 weeks postpartum. Postpartum psychosis is a break from reality that includes delusions that the mother believes are reality.

Postpartum psychosis is treatable with professional help and it is imperative to get treatment immediately.

Symptoms may include:

- Hallucinations
- Irrational thinking
- Rapid mood swings
- Difficulty communicating at times
- Paranoia and suspiciousness

POSTPARTUM PSYCHOSIS is considered an **EMERGENCY** and the mother needs to be assessed and treated **IMMEDIATELY**.

Call your doctor or take your loved one to the ER immediately.



LET'S TALK THERAPY

Professional therapeutic support can help you navigate the many emotions surrounding an AFE and decrease potentially negative symptoms and behaviors. Sometimes getting started with therapy can be challenging. The information below will assist you in learning the various types of support professionals, common forms of therapy, and how to find one that is right for you.

Types of Support Professionals

- **Psychiatrist:** A medical doctor who can diagnose, prescribe medication, and offer various therapeutic services.
- **Psychologist (PsyD, PhD):** A doctorate level clinician who can diagnose and offer therapeutic services but cannot prescribe medication.
- **Licensed Professionals and Associates (LMFT, LCSW, LSW, LPC, LMHC, etc.):** A Masters level clinician that can diagnose and offer various therapeutic services.
- **Psychiatric Nurse Practitioners** and **OBGYNs** do not provide therapy, but can prescribe medication.
- **Life Coaches** do not provide therapy and are not trained or licensed to work with trauma. They may be helpful with sleep, parenting, or career coaching.
- A **Perinatal Mental Health Specialist** is a therapist specifically trained to work with women around complex emotions related to pregnancy, birth, and postpartum.

Find a therapist close to you through [Postpartum Support International](#) or [The Postpartum Stress Center](#).

HOW TO FIND A THERAPIST

Through Your Insurance Company


- You can either call the number on the back of your insurance card or use the insurance company's website portal.

Therapist Directories, Websites, and Organizations

- postpartum.net
- postpartumstress.com
- psychologytoday.com
- openpathcollective.org
- birthandtraumasupportcenter.org

Women of Color Focused Therapy Directories

- providers.therapyforblackgirls.com
- melaninandmentalhealth.com
- blacktherapistsrock.com



It may take
a few attempts
to find the
therapist that meets
your needs so
don't get discouraged!

COMMON TYPES OF THERAPY FOR TRAUMA

Cognitive Behavioral Therapy

Cognitive behavioral therapy, or CBT, is a common form of psychotherapy, and focuses on how thoughts and beliefs influence feelings, behavior, and physical sensations. It aims to help identify and reshape negative thoughts and belief patterns.

Somatic Experiencing Therapy

Somatic experiencing therapy focuses on a physical body approach, rather than on thoughts and feelings. Treatment may include mindful breathing, sensory awareness, and progressive muscle relaxation with the goal to have sensations in the body help release trauma energy.

Narrative Therapy

Narrative therapy helps form a cohesive story or narrative of the trauma to help make meaning of it. Re-storying or retelling the trauma from different perspectives or by adding new characters can add a sense of meaning, or hope to a traumatic event.

Eye Movement Desensitization and Reprocessing

Eye Movement Desensitization and Reprocessing, or EMDR, therapy is designed to resolve unprocessed traumatic memories in the brain. Treatment includes picking a target memory or word that represents the trauma and using bilateral stimulation including eye movement or tapping to reprocess the memory and lower the stress of the event or memory. It is believed that recalling stressful or traumatic events is less emotionally upsetting when your attention is diverted. Click [here](#) to learn more or help find an EMDR clinician.

THERAPY FOR PARTNERS AND SPOUSES

Partners and Spouses are also likely to need support following an AFE. Symptoms of post-traumatic stress disorder and postpartum depression seem to be interlinked within a couple, as shown in [several studies](#). Of the women who develop postpartum depression, 50% of their partners will also develop PPD. [The Men's Center for Excellence](#) is a great resource for partners/spouses.



KAYLEIGH, BIRTH TRAUMA EXPERT AND CONTRIBUTING AUTHOR

I had an AFE in 2019 during the birth of my son, Callahan. While I was in the ICU on ECMO, my family found the AFE Foundation and used its survivor guide to help me navigate through my hospital stay and returning home.

Once home, I found it very comforting to connect with others in the [AFE Foundation AFE Survivor Support Group on Facebook](#). I learned that so many of us shared similar challenges. As a licensed social worker, I know a lot about emotional healing. However, I quickly recognized birth trauma is unique and complex. The more I learned, the more I shared and found solace in serving others in the birth trauma community.

My greatest hope is that you find the information included in this guide will help you like it helped me.

Read Kayleigh's bio or find her on social media where she shares more about navigating the often difficult and emotional road after AFE: @thebirthtrauma_mama on Tik Tok and Instagram.

AFFORDABILITY

Therapy can be expensive and is a common barrier when seeking treatment. While insurance may include therapy in their covered benefits, the selection of therapists and the services they offer are limited or not available in certain areas. There are a few other options available to seek affordable mental health therapy.

Employee Assistance Program (EAP)

If you work for an employer, your company may provide EAP benefits which allows employees to receive support for mental health concerns that may be interfering with their work. Many symptoms of trauma or PTSD affect executive functioning leaving you unable to prioritize, multi-task, organize, or focus. Contact your human resource representative You can find more information on EAP counseling [here](#).

Open Path Collective

[Open Path Collective](#) is a non-profit organization that serves clients who lack health insurance or whose health insurance doesn't provide adequate mental health benefits. After paying a membership fee of \$59, the subscriber will have access to therapy for \$30-\$60 per session.

If you need any assistance in finding the right support, please don't hesitate to [contact us](#).

CONNECTING WITH OTHERS

AFE Foundation Specific Support

The AFE Foundation offers several ways to connect with others. Our Facebook support groups help survivors and their family members connect with others who truly understand the challenges faced after surviving an AFE. We hope you'll consider joining.

[AFE Survivors](#)

[AFE Survivors with Infant Loss](#)

[AFE Survivors: Pregnancy After an AFE](#)

[Family of AFE Survivors Support](#)

AFE Foundation LCSW Facilitated Zoom Groups

Several times a month we offer small group peer support facilitated by a Licensed Clinical Social Worker and birth trauma expert. Although it does not offer specific individual cognitive behavioral therapy, the meetings allow you to connect in a more personal way and learn from one other. If you are interested in joining, [contact us](#) and we will provide more information on times and dates.

AFE Foundation Survivor Directory

To help you connect with others who may share similar experiences and perspectives, we offer a password protected expansive and searchable directory and map. To get access to the directory [contact us](#).

Being a member of the AFE group has helped me understand that *I am not alone in my recovery*. It has helped me put my challenges into perspective and realize that there are so many different levels of suffering. This group has provided a place that I feel is *safe* to put all of my feelings out there because I know each and every one of you will understand and for that, I am so grateful.

- Donna F., suffered AFE in 2000

I felt so alone, empty, confused, and angry before I joined this group. Without this group I wouldn't have been able to cope on my own. My husband and my family are not able to talk about the event. The women in the group have been a *constant source of comfort* after losing my child from AFE.

- Carol D., suffered AFE in 2006

I woke up in the ICU in so much pain and didn't know what happened. I spoke to one of the OB doctors who explained that I had an AFE. He told me about the AFE Survivor Support Group on Facebook and as soon as I got home I looked it up and joined. I attended my first zoom support group and I immediately knew I could *find support and comfort*, and have already made friends with AFE sisters that understand what I am going through.

- Ziri C, AFE Survivor 2020

Community Based New Mom Groups

There may be new mom support groups in your local community such as at hospitals, community centers, libraries, or through social media meetups. These are wonderful ways to connect with other moms in your area. However, it is important to be mindful that members of these groups will most likely have had uncomplicated pregnancies and births and may not understand some of the complexities that encompass birth trauma and surviving an AFE.

Online Birth Trauma and New Parent Support Groups (Non- AFE Specific)

[Birth Trauma Association Group](#)

[Birth Trauma Support Group](#)

[Maternal Near Miss Facebook Support Group](#)

[Hysterectomy to Survive Complication of Pregnancy Support Group](#)

[Women of Color with PPD by the Shades of Blue Project](#)

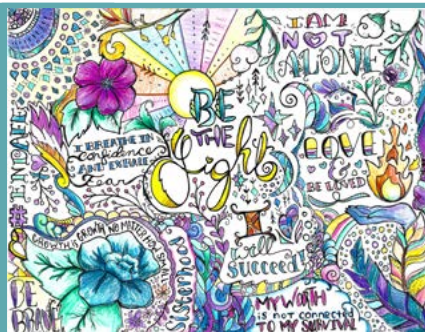
[LGBTQ New Parent Support Group](#)

CHECK OUT OUR AFE

Survivor Reflective Coloring Page

DESIGNED BY ARTIST AND AFE

SURVIVOR, LIANA ALBERS.



SELF-CARE AND OTHER RESOURCES

We've all heard the airline rules to "put your oxygen mask on first, then place it on your children." It's simple and potentially life-saving advice that is an easy metaphor for self-care. Self-care is the practice of caring for your own mind, body, and spirit with dedicated actions to reduce stress and increase wellness.

Self-care is essential for AFE survivors. However, it can be tremendously challenging to carve time out for yourself, especially if you are still recovering from your AFE and are caring for your baby or are grieving. So often our, and our babies, healthcare needs are the priority and leave little time to focus on the emotional and or spiritual recovery.

The [National Institute for Mental Health](#) says, "although self-care is not a cure for mental illnesses it can play a role in maintaining your mental health and help support your treatment and recovery".

Self-Care Activities from [Psychology Today](#)

- Breathe in fresh air
- Snuggle under a cozy blanket
- Mindful coloring
- Take a hot shower or a warm bath
- Go for a walk or drive
- Cuddle with a pet
- Burn a scented candle
- Stare up at the sky or clouds
- Take a nap
- Listen to music
- Write in a journal
- Spend time in nature
- Pray
- Call a friend
- Stretch

SELF-CARE ACTIVITIES

FROM PSYCHOLOGY TODAY



BOOK RECOMMENDATIONS

The Body Keeps Score

More Than a Healthy Baby

Good Moms Have Scary Thoughts

Option B

The Boy who was Raised as a Dog

Walking the Tiger

Between Two Kingdoms: A Memoir of Life Interrupted

The Boy, The Mole, The Fox, and The Horse

Birth Trauma: A Guide for You, Family and Friends

Why Birth Matters

How to Heal a Bad Birth

SELF-CARE APPS

Use your mobile device to help you restore your mind, body and spirit.

- Calm
- Headspace
- Aura
- Insight Timer
- Simple Habit
- Audible
- MyLife

APE 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 section is some information compiled from others in your same situation. We hope it helps guide and comfort you.

31 SPEAKING ABOUT INFANT LOSS

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32 ANNIVERSAIRES

ACCEPTING YOUR NEW BODY

VISITS TO THE OBGYN

33 PREGNANCY AFTER LOSS

LACTATION AFTER INFANT LOSS

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COMPLICATED GRIEF

MANIFESTATIONS OF GRIEF



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.

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.

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.

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.