

AFE SURVIVOR FREQUENTLY ASKED QUESTIONS

AMNIOTIC FLUID EMBOLISM (AFE) is a sudden and unexpected life-threatening birth complication that can affect both mother and baby. Although poorly understood, it is thought to be the result of an allergic-like reaction to the amniotic fluid that enters the mother's bloodstream, a normal part of the birth process. It most often occurs during labor or shortly after delivery.

AFE is a complex medical condition that can be very difficult to understand, most especially if you have been personally affected or are currently facing an AFE crisis.

This is a comprehensive list of 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 women'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 \(CMQCC\)](#).

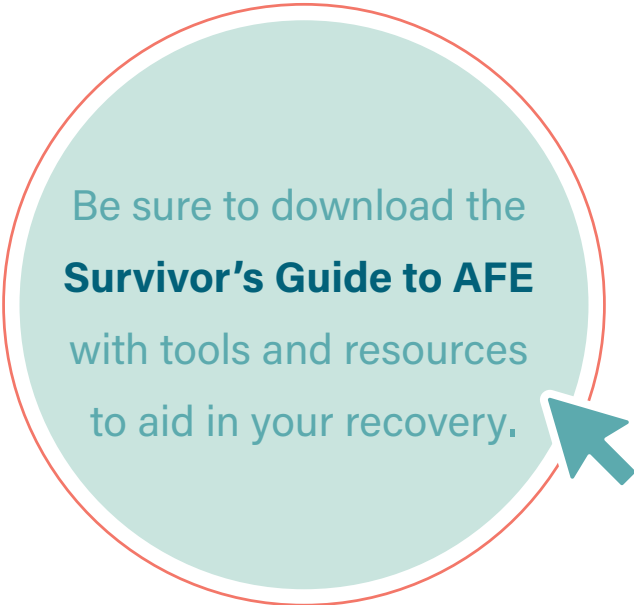
Some medications used in labor induction will list amniotic fluid embolism as a potential risk. These medications are commonplace but used as off-label drugs, meaning they were developed for other medical conditions. When off-label medications are used, it means during drug development no studies looked 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 and one when all information is presented and the risks and benefits to both mother and baby are clearly understood and consented to.



Be sure to download the **Survivor's Guide to AFE** with tools and resources to aid in your recovery.

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

#ENDAFE