



# Amniotic Fluid Embolism

**We are here to help. Our organization was created to support families like you.**

Amniotic fluid embolism (AFE) is a complex medical condition that can be difficult to understand. This handout includes answers to frequently asked questions, a place to keep important information, and things you can do right now.

**Amniotic fluid embolism or AFE** is a rare birth complication that can cause sudden and life-threatening breathing, blood pressure, and bleeding issues.

## WHAT CAUSES AN AFE?

The exact cause of an amniotic fluid embolism (AFE) is not well understood. It is believed to be the result of a severe, allergic-like reaction to something in the amniotic fluid. There are no known risk factors for AFE.

## HOW IS AN AMNIOTIC FLUID EMBOLISM TREATED?

Immediate life-saving care is necessary to treat the breathing, blood pressure and bleeding symptoms. This care may include medications, breathing tubes, chest compressions, blood transfusions, and/or surgeries. If the baby was not delivered before the AFE event, the baby may also require life-saving treatment.

## IS THERE ANY WAY TO PREDICT OR PREVENT AN AFE?

Since it is not understood what causes an AFE, it is impossible to know who may be at risk. The words unpreventable and unpredictable are often used to describe AFE.

## HOW IS AFE DIAGNOSED?

There is no diagnostic test for AFE. It is diagnosed based on the timing of symptoms and ruling out other causes. It may take several days for the healthcare team to determine the diagnosis and often will include the words "proposed" or "suspected".

## HOW RARE IS AFE?

The true rate of AFE is unknown but is estimated to be 1 in every 40,000 births. There are ~4 million births a year in the U.S. and ~100 will experience an AFE.

## WHAT IS THE SURVIVAL RATE?

Similar to incidence rates, rates of survival are not well understood. Survival rates are estimated to be between 40-60%. Survival depends on many factors, but most significantly is the severity of the initial immune response.

## QUICK TIPS FOR FAMILY MEMBERS:

1. Contact immediate family members, loved ones and clergy/spiritual advisors who you may want to come to the hospital.
2. Identify someone who will help share information to others. You will be very busy and cannot update everyone.
3. Ask someone to help take care of other children and/or pets.
4. Take pictures and videos of your baby (even if critically ill or deceased) and of your loved one. You may think you don't want these pictures now, but someday you may want them.
5. Take notes and/or audio recordings if allowed. You will be receiving a lot of information and making many decisions that you may want to reference later.

If you are trying to explain this to family and friends, here are some quick facts you can share:

**Rare, 1 in 40,000 Births**

**No Known Risk Factors Unpredictable**

**Unpreventable**

**No way to diagnose an AFE other than to rule out any other conditions it could have been**



Scan this QR code to get a digital version of this handout that you can quickly share with friends and family. Visit our website for more information and support.

**KEEP TRACK OF IMPORTANT INFORMATION AND NOTES ON THE BACK OF THIS HANDOUT** →

## AFE Research: We need your help

If you are open to it, *please ask your healthcare provider to not throw away any of the blood that was taken during your loved one's care* and may still be in the lab.

These blood samples are usually discarded as medical waste, but can instead be sent to our organization to further AFE research.

Learn more about our research at [afesupport.org/research](https://afesupport.org/research)



# Amniotic Fluid Embolism

## IMPORTANT INFORMATION TO REMEMBER

Hospital Name and Address: \_\_\_\_\_

\_\_\_\_\_

Name of OBGYN: \_\_\_\_\_

\_\_\_\_\_

Name of Labor Nurse: \_\_\_\_\_

\_\_\_\_\_

Name of NICU Nurse: \_\_\_\_\_

\_\_\_\_\_

Name of ICU Nurse: \_\_\_\_\_

\_\_\_\_\_

Name of Social Worker: \_\_\_\_\_

\_\_\_\_\_

Notes/Questions: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_