



SEEKING ANSWERS. OFFERING SUPPORT.

FAMILIES IN HEALING - GUIDE FOR WOMEN RETURNING HOME AFTER AFE

If you have a loved one who has experienced amniotic fluid embolism (AFE) and they are about to or have returned home, we are here to help. AFE can have lasting physical and emotional affects that can be overwhelming. The following information is intended to assist you during the weeks, months and years after returning home from AFE. This information has been compiled by speaking with families who have experienced AFE. These are things they found to be most helpful. It is not intended as medical or legal advice and it is always recommended you seek professional guidance with any questions as they relate to your specific situation or condition.

*We recognize that every situation is unique and the following is not all-inclusive. We encourage you to reach out to us at info@afesupport.org at any point to assist you with your particular needs or questions.

Helpful information for the weeks, months and years following AFE:

Questions after surviving AFE

The AFE Foundation recognizes the uniqueness of each woman's path towards healing. However, there seems to be common questions and concerns that most AFE survivors share. Please visit our Frequently Asked Questions section that addresses many of these topics.

Obtaining support from governmental agencies

Your loved one may qualify for extra time off of work and/or monetary support from various governmental agencies. It is important to understand what benefits are available to you.

- **Disability**

Mothers most often qualify for short-term disability benefits during their postpartum recovery. The physician in charge of your loved ones care or the hospital where the AFE occurred can provide the necessary paperwork to place a disability claim. More information about disability benefits through Social Security may be found at (<http://www.ssa.gov/pubs/10029.html>)

- **Family Medical Leave Act**

Additional assistance may be available through the Family and Medical Leave Act (FMLA). More information about FMLA can be found at (<http://www.dol.gov/compliance/laws/comp-fmla.htm>)

If there is greater need for financial assistance there are a variety of programs available to help subsidize food, formula, medical coverage and daycare assistance through the Women's Infants and Children (WIC) program. For more information on qualifying for these benefits visit (<https://stars.fns.usda.gov/wps/pages/start.jsf>)

- **Access to Local Resources**

2-1-1 is a national organization that can help connect individuals to resources in selected communities throughout the US and Canada. To see if your city is listed, visit (<http://www.211us.org/status.htm>). If your city is listed, dial 211 from your phone to be connected with a representative who will listen to your needs and connect you with the appropriate local organizations.

- **Assistance in the UK**

For information regarding governmental support in the United Kingdom visit Directgov at (<http://www.direct.gov.uk/en/index.htm>)

- **Assistance in Australia**

For information regarding governmental support in Australia visit Centrelink at (<http://www.centrelink.gov.au/>)

Obtaining support from your employer

Check to see if your employer offers an Employee Assistance Program (EAP). EAP's are intended to help employees deal with personal problems that might adversely impact their work performance, health, and overall well-being. EAP's generally include short-term counseling and referral services for employees and their household members.

Some employers will allow fellow employees to donate time off to employees in need. Check to see if this is available. If so, consider asking a close colleague or manager to send an email to other employees on your behalf.

Don't be afraid to speak up and ask for what you need from your employer. Severe complications during childbirth are rare and your employer may not have a precedent for dealing with the situation.

Be sure to contact the employer that provides the health care benefits to add your new baby to the health insurance policy. Obtain a full copy of the benefits package and a copy of the "summary plan" document. These will clearly identify the benefits and programs available to you.

Managing Medical Bills

Once discharged from the hospital, medical bills will begin to arrive. Get a large three ring binder to store medical bills and Explanation of Benefits (EOB) and as they come in. If your child was admitted to the NICU, create a separate binder for their bills. This will not be a priority for several months. It is recommended to wait 2-3 months before paying medical bills to allow the insurance company and providers to work out any conflicts or billing issues.

Once this occurs contact the insurance company and request to have one liaison to help manage your case. It is in your and their best interest to have one person be familiar with your claims. Ask for this person's direct line and email. Email is the preferred method of communication, as it will provide a written record of the correspondence. If the insurance company will not provide a special representative, contact the employer who provides the medical benefits and ask if they have a contact at the company. If this is not an option, ask for a supervisor as they often have more authority and access to more information. Make notes in the binder for each conversation with the insurance company. Write down the date, time, name and ID of each representative and what was discussed.

If someone other than your loved one is managing the medical bills be sure to ask the insurance company how to establish authority to discuss claims and coverage as your loved one is unable to do so themselves.

For more information about how to understand your medical bills and explanation of benefits visit the following helpful websites.

Your Medical Bills at (<http://yourmedicalbills.com/>)

Family Doctor.org at (<http://familydoctor.org/familydoctor/en/healthcare-management/insurance-bills/understanding-your-medical-bills.html>)

Patient Empowerment at (<http://patients.about.com/od/costsconsumerism/ig/Read-a-Medical-Bill/>)

Obtaining a Complete Copy of Medical Records

It is also HIGHLY recommended you request a FULL copy of your medical records and any and all images from the hospital as soon as possible. Hospitals are only required to keep records for a specific amount of time.

To obtain your records, contact the main hospital phone number and ask to be connected with the records department or visit the hospitals website. You will need to complete a medical information release form. Your records may contain several hundred pages and images. Most often the records department will encourage you to take just the discharge summary, YOU NEED TO HAVE THE COMPLETE FILE. The discharge summary will not list medications or dosages. These are important to have. Most hospitals will charge a fee per page. You have a few options to try to avoid these fees. You may speak with the case manager about how to obtain these and request them at no charge. You may also have your physician request a complete copy and ask them to give it to you. Hospitals typically do this at no charge to the care providers. If you need further assistance requesting or paying for your records please send us a message at info@afesupport.org.

Maintain all of your records and images in a box or binder for future reference.

Continuity of Care

One of the greatest challenges of AFE is the lack of understanding that accompanies it. This also impacts the management of potential complications that arise in the weeks, months and years following AFE. Some women are able to make a full recovery while others will struggle with various health issues. It can be extremely challenging to find the right team of doctors to help care for your loved one once she returns home. You may want to ask the physicians in the hospital if they also are in private practice or for a recommendation of care providers in the area.

Your loved one will continue to be under the care of an OBGYN but may need other specialists to address complications from the AFE. Many AFE survivors report being under the care of various specialists. These may include but are not

limited to cardiologists, neurologists, pulmonologists, hematologists, nephrologists, psychiatrists, and primary care physicians. It is recommended you have one physician manage your care and receive all reports from the other specialists. Communication between these doctors is essential so they can work together to determine the best course of action. If they are unwilling to send reports to another physician, obtain a copy of your records from each visit. Add these to your medical information binder with your hospital records.

Be sure to have the primary physician in charge of your care also request copies of your complete medical records from the hospital.

Psychological Support

It is common to suffer from Post-Traumatic Stress Disorder (PTSD) and/or Postpartum Depression as a result of experiencing a traumatic childbirth. It is also common for fathers and close family members to suffer from some form of PTSD following AFE.

For more information about PTSD visit the following helpful links:

Pub Med at (<http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001923/>)

Mayo Clinic at (<http://www.mayoclinic.com/health/post-traumatic-stress-disorder/DS00246>)

For more information about Postpartum Depression visit these helpful links.

Pub Med at (<http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0004481/>)

Mayo Clinic at (<http://www.mayoclinic.com/health/postpartum-depression/DS00546>)

The following organizations offer support to help manage these conditions:

[Solace for Mothers \(http://www.solaceformothers.org/\)](http://www.solaceformothers.org/) is an organization designed for the sole purpose of providing and creating support for women who have experienced traumatic childbirth.

[The Birth Trauma Association \(BTA\)-UK \(http://www.birthtraumaassociation.org.uk/\)](http://www.birthtraumaassociation.org.uk/) supports all women who have had a traumatic birth experience. It is estimated that, in the UK alone, this may result in 10,000 women a year developing Post-Traumatic Stress Disorder.

[Postpartum Support International \(http://www.postpartum.net/\)](http://www.postpartum.net/) is dedicated to helping women suffering from postpartum depression.

[Helpguide.org](http://helpguide.org) (<http://helpguide.org>) is a non-profit that provides access to helpful information and resources related to various mental, emotional and lifestyle challenges, including [Post-Traumatic Stress Disorder](http://helpguide.org/topics/ptsd_trauma.htm) (http://helpguide.org/topics/ptsd_trauma.htm) and [Postpartum Depression](http://helpguide.org/mental/postpartum_depression.htm) (http://helpguide.org/mental/postpartum_depression.htm)

Connecting with Other AFE Families

The AFE Foundation has created a support group for anyone who has been affected by AFE. With over 450 members the group has helped women and family members connect with other who truly understand the challenges faced after surviving AFE.

Here is what some of the members of our support group are saying.

“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 able to talk about the event. I've become good friends with some of the women in the group and they been a constant source of comfort after losing my child from AFE.”

-Carol D., suffered AFE in 2006

“I found what happened to me to be a very isolating experience for a long time until I learned it was an AFE and found this group. It's so difficult to talk to anyone outside of the group about the experience. However, I know I can openly discuss within the group if I need to with people who understand and care.”

-Laura P., suffered AFE in 2009

“There is an immediate bond and understanding between us. You are on a journey from the moment you suffer from AFE, its such an utterly frightening thing to happen and so unexpected that I felt my world tilted off it's axis. Finding this group put my world back in order. I realized it wasn't anything I had done and I wasn't alone. I take such complete comfort from the deep friendships I have with women who totally understand how I feel and I know we will always be there for each other.”

-Melanie S., suffered AFE in 2006

To connect with our support group you must be a member of Facebook. If you are not a member of Facebook but would like to connect with others who have experienced AFE, please send us a message at info@afesupport.org and we will help connect you to others.

AFE Foundation Support Group

(<https://www.facebook.com/groups/AFEFOUNDATION/>) The AFE Foundation Support Group is for anyone affected by AFE. The group is a private group which means membership is required and content is only accessible by members. This group was established and will be moderated by the AFE Foundation.

AFE Foundation Fan Page < <https://www.facebook.com/amnioticfluidembolism>>

Please click “Like” on the Foundation’s fan page for the most up to date information from the Foundation. You may also click the “Stay Connected” button to receive important communications and updates from the AFE Foundation.

AFE Foundation Blog (<http://amnioticfluidembolism.wordpress.com/>) The AFE Foundation Blog is a place where those whose lives have been impacted by AFE can share their stories with one another in order to provide greater support and information. Suffering from AFE can be a very lonely, troubling, and frightening experience. This site will provide information about specific cases of AFE as well as what individuals did to cope.

Amniotic Fluid Embolism Support Group in Australia
(<https://www.facebook.com/groups/163830520353560/>)

This group is for women looking to connect with others in Australia and is not moderated by the AFE Foundation.

Additional stories of women who have suffered AFE can be found on our website under stories.

Books written by AFE Survivors about their experiences

Some AFE survivors have gone on to document their stories in a book. While both come from a different perspective, they both provide a great deal of comfort in knowing you are not alone.

For more information visit our website to learn more about each book and how to purchase them.

The Day I Died by Melanie Pritchard

A Journey to the Son accompanied by music CD by Lauren Braddock Havey

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