



SEEKING ANSWERS. OFFERING SUPPORT.

## **FAMILIES IN CRISIS – GUIDE FOR WOMEN STILL HOSPITALIZED**

If you have a loved one that has recently experienced AFE, we are here to help at every step of the way.

Amniotic fluid embolism (AFE) strikes unexpectedly and can have a tremendous impact on everyone involved. Family members facing a medical crisis are often emotionally overwhelmed and unable to use traditional coping skills and problem solving.

The following information is intended to assist you during the time immediately following AFE. This guide is for patients who are still hospitalized and has been compiled by speaking with families who have experienced AFE. These are some of the things they found 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.

### **Helpful steps and information for the hours and days following AFE:**

#### **Asking for and receiving help**

Allow people to help. One of the most common responses we hear is that sometimes you don't know what help you actually need or anticipate needing. Many of the items on this list can be done or started by someone else. Ask a close family member or friend to help manage the tasks below or identify someone that may be best suited for each item. You will find many people will want to help, even strangers. Be sure to keep contact information of those offering to help; you may not have an immediate need but may discover one at a later time.

#### **Communicate your loved one's condition efficiently using a website.**

Spouses and family members can spend precious hours providing updates to other family, friends, neighbors and coworkers. Instead, designate one person to be the director of all communications and determine the most effective and efficient way to communicate with others.

We recommend using a website to communicate your loved one's condition and highlighting the family's needs. There are specific companies that have designed FREE and EASY to use website templates specifically for those facing a medical crisis.

Helpful items to include on a website are daily updates, photos, as well as listing specific ways people can help such as prayer requests or spiritual assistance, meals, flowers, monetary donations, etc. Be sure to also include whether you would like visitors and list those times. Priority should be rest for patient as well as family. Consider having a guestbook for well-wishers to leave messages of hope and comfort rather than visiting. The guestbook has proven to be exceptionally helpful during the recovery process.

Listed below are organizations that offer websites and personal blogs:

Caring Bridge (<http://www.caringbridge.org/about>)

Care Pages (<http://www.carepages.com>)

Lotsa Helping Hands (<http://www.lotsahelpinghands.com>)

### **Visitors**

Upon hearing the news of your situation, many will want to come to the hospital to visit or simply be near the family. Be mindful that visitors can be very tiring and can interrupt important periods of rest. Your loved one's critical condition will require countless medical staff to come in throughout the day and evening, thus limiting opportunities for rest. Also, be aware of cold and flu season as stress can decrease the body's defense system and make you more susceptible to viral infections. This consideration should be made for mother as well as the caretakers. With increased technology consider asking loved ones and well-wishers to send videos of encouragement and support. This way your loved one may view them when able and as often as they would like.

### **Caring for a newborn while the mother is in crisis**

It can be extremely challenging to manage the care of your loved one in addition to caring for a newborn child. If the baby was delivered and is stable the baby will most likely remain in the NICU or nursery for a few days. If this has not yet been addressed you may want to speak with the case manager at the hospital or the physician on duty to have the baby admitted into the NICU or newborn nursery while your loved one remains in critical condition. It is also very common that the NICU will adhere to a strict visitor policy and only allow the father and grandparents to see the baby. Consider the option to have one person in charge of the baby's care and one person in charge of the mother's care. It will be important to have that person attend all physicians' consults. This can be logistically impossible for one person to manage both. This will be especially important if the baby suffered complications during delivery and will require numerous medical decisions.

While many people will want to see and visit the NICU or nursery, please consider the mother's feelings and be mindful of passing potentially harmful germs or illness.

Discuss feeding options with the NICU and nursery staff. Depending on the baby's condition, they may begin with IV fluids or may immediately receive formula. If the mother had planned on breastfeeding, she still may be able to once she becomes stable. Even if the baby is given formula the mother may still be able to breastfeed. Once stable, she may begin to pump her breast milk and eventually breastfeed once medications have cleared her system. This is a very delicate decision and should be made with consideration for the mother's previous intentions and what is in the best interest for her health. It is okay to encourage the mother to breastfeed if she is able. It is equally important to assure and comfort her if she is not able or desires not to breastfeed. The most important priority should be on the mother and baby's health and their ability to bond.

If both the baby's and the mother's conditions allow, learn what the hospital's guidelines are for having the baby spend time with the mother in ICU. If this is not possible have photos taken of the baby and place them in the hospital room for the mother to see. It can be a very isolating experience for the mother not to have seen or spent time with her newborn. Photos will help bridge this gap and provide a small connection for the mother to have until she can be with the baby in person. It is also recommended to have photos of older children, pets or other memorable photos in her room.

If the baby is released before the mother try to identify one or two people who will help the father manage the baby's schedule. Please be mindful that it will be extremely painful for the mother to not be the primary caregiver and it can be challenging to process these emotions. Choosing someone who is respectful of these feelings and with whom the mother would be comfortable with is essential. Have those caring for your infant and/or other children maintain a daily log of their activities and milestones. These will prove very helpful during the mother's recovery.

Contact the employer who provides the health benefits and be sure to add the baby to the policy. This is very important to do as soon as possible to avoid any medical billing issues. Be sure to provide the hospital with the updated information.

### **Caring for older children while the mother is in crisis**

The emotions and needs of older children will vary depending on the children's age. Confusion and fear are the most common emotions older children will experience while the mother is in the hospital and during the recovery process. Older children can feel sad, isolated, angry and alone. It is important to keep their routine as normal as possible. You may wish to have them stay with a close relative or friend in the days immediately following the AFE to limit their exposure to the stress of the situation.

Consider asking friends to give gifts to older siblings instead of for the new baby. New toys, games, books or videos may provide a welcome distraction.

Hospital social workers may be a helpful source of advice and should be able to provide helpful resources to assist with explaining the situation to the child(ren) in an age-appropriate way.

It is also important for others who will be interacting with the child(ren) on a regular basis (daycare providers, teachers, etc) to be aware of the family's situation. Children may manifest their stress in unexpected ways and depending on the age, this could include regression in potty training, unusual tantrums, anger, withdrawal, difficulty napping, etc. It is important that those interacting with your child fully understand the situation and are able to respond empathetically to unexpected behavior.

### **Documenting the event for the mother and child**

- **Photos and Videos**

Delegate someone to be in charge of taking photographs and videos of the baby and those coming to visit mom. Many of the women who survive AFE will suffer from short-term and/or long-term memory loss and will be very curious about what happened while they were hospitalized. They may appear to understand what is happening initially but will likely forget much of what transpires due to the trauma and heavy medications. While many may not be joyful photo opportunities, several women who have recovered have expressed that they wish they could see evidence of what they experienced. Consider taking the photos and holding them until your loved one is ready to see them.

- **Start a Journal or Log**

Write things down so there will be a record of what happened while the mother was in the hospital. Keep a detailed journal of your loved ones daily activities and thoughts. Write about the days or hours before the delivery as most survivors who suffer a coma or heavily sedating drugs will not be able to recall those memories. Include the names of physicians nurses, respiratory techs, physical and occupational therapists and any other service provider you encounter. These will be important for future reference to address concerns or offer notes of appreciation. Keep the journal by the bed so it can easily be accessed. Electronic tablets or iPads are great tools to help document the event.

Even as a spouse, family member or caregiver, your memory will likely be unreliable for some time.

- **Keep a detailed medical record for future reference**

In addition to the information above, you will also want to have a detailed record of medical information to refer back to during the recovery process and beyond. Unfortunately, medical records can often be incomplete and/or hard to decipher. Keep as detailed notes as possible. Include medications, dosing, and information from updates with physicians, etc. The mother may end up seeing multiple medical professionals from various specialties for follow-up

care. It will be helpful to have your own accurate record of the care that the mother receives during the immediate recovery process.

It is also important to write down details of what occurred during the AFE (including the medications administered prior to delivery and any other pregnancy related issues that arose prior to delivery). It will prove helpful to be able to refer back to these details for years to come.

This information may also prove useful when sorting through medical bills.

## **Managing offers of help and visits from well-wishers**

- **Visitors**

Determine what your family's preference is regarding visitors. Most hospitals will have strict policies in place that regulate visitors-especially while your loved one is in critical condition. Designate one family member or friend to help coordinate visits. This is also where it can be helpful to have a website to help communicate the family's preferences with regard to visitors.

- **Meals**

When your loved one has been released from the hospital many people will often volunteer to deliver a meal as a way to offer assistance. Ask a family member or friend to coordinate the process and spread the word to others who may want to participate. Include friends, co-workers, neighbors and church members.

Set a specific time for meals to be delivered. If it is too difficult for the family to speak with each person delivering meals, try to arrange to have someone at your home to accept each meal. You may also consider requesting meals be left in a cooler placed by the front door.

Determine the portions needed or have the meals planned to come every other day. Otherwise, your fridge could fill up very quickly and become hard to manage. Have the coordinator be in charge of making sure the fridge is cleaned out once a week.

Be sure to make note of any food allergies, preferences or limitations. Have the coordinator keep a log of people who provide meals and their contact information so you can offer words of appreciation at a later time.

Below are a few websites that help coordinate meal deliveries with ease.

[CareCalendar \(http://www.carecalendar.org/\)](http://www.carecalendar.org/)

[Meal Train \(http://www.mealtrain.com/\)](http://www.mealtrain.com/)

- **Groceries**

Groceries will be another important task that can be given to others in the days and weeks after your loved one is home. Have someone itemize what the family's preferred brands/sizes are and make a list of essentials such as milk, bread, eggs, fruits, toilet paper and paper towels. Most of the daily meals will likely be provided but having the basics and snack items handy will be especially helpful if you have older children.

### **Personal Time for Caregivers**

It is important to take at least 30 minutes to an hour each day to have to yourself if you are a caregiver. This is vital for you to replenish your mind, body and spirit. However you decide to spend this time is up to you. Express to family and friends the importance of having time away. Some common tips have been going to the gym, coffee shop, church or place of worship. If you have a hobby, be sure to continue to do that. Depending on the time of year, getting outside can be very beneficial. Reading the newspaper or watching your favorite shows will also help keep a sense of "normalcy" during this stressful time.

### **Connecting with other AFE Families**

#### [AFE Foundation Support Group on Facebook](https://www.facebook.com/groups/AFEFUNDATION/)

(<https://www.facebook.com/groups/AFEFUNDATION/>) The AFE Foundation Support Group is for all individuals affected by AFE. The group is a private group which means membership is required and content is only accessible by members.

[AFE Foundation Blog \(http://amnioticfluidembolism.wordpress.com/\)](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 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.