



WHAT IS IT LIKE TO HAVE A BABY WITH CONGENITAL DIAPHRAGMATIC HERNIA?

Imagine that you and your partner are expecting a baby. The thrill of the whole thought – another little being. The whole thing is a bit overwhelming and exciting. About the time many are diagnosed, is the 20 week ultrasound. Most couples go to the doctor excited to perhaps find out the sex of the baby and/or just to get a glimpse of this little one before they are born. Whose mouth and nose does this little one have? No one expects to be told their child has something wrong.

You are in a darkened room in order to see the ultrasound monitor and the tech is actually measuring the size of the head, bones and checking to see the organs. Then they see that something isn't right. It is hard to not disclose this to the couple who is excited to see their baby, the hands the feet the nose. In that darkened room or perhaps after you are led to an office after the ultrasound, a health professional will then inform you that your unborn child has a birth defect called congenital diaphragmatic hernia. The survival rates are approximately 50 to 60% and they must tell you that the treatments they endure to save their lives may cause lifetime issues. They also have to tell you that congenital diaphragmatic hernia itself because the child's organs did not form correctly in development may have lifetime issues.

You are then told there are options. Fetal surgery may be an option but depending upon where you live and the availability of surgeons who specialize in this, it could not be a financially feasible one. It also depends upon the mother's overall health and the severity of the diaphragmatic hernia, so you must qualify to have this option available to you too. Your insurance coverage may not cover such a procedure. It is highly experimental even today. One day it may not be. You are also told that you should have this infant, if you continue this pregnancy at a level 3 or higher NICU at a Medical Center that has had experience, even with the fetal surgery you would need this too. They may require ECMO, a heart lung bypass in order to save their lives. To imagine your unborn child hooked up to a heart lung bypass? It is overwhelming. This isn't supposed to happen.

You will also be given an option to terminate the pregnancy. You just passed the 12 week point where many couples start to breathe easier because you are past the crucial point of miscarriage in the first trimester. You are not supposed to be making life and death decisions for your child. You are supposed to be planning the nursery, picking out clothing and the only worry will be if you truly think you are up to being a mother or a father. Those worries are enough in themselves.

Now you are given options if you were prediagnosed prior to birth. You must make these decisions that will not only affect your lives, but your whole family. You will wonder if your choice of hospitals is good and question if you should go to another. None of the choices are easy. You will also be asked to

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undergo an amniocentesis to rule out any other abnormality with this unborn child. Many times there are none. Sometimes there are other issues.

Only other parents who have faced this understand the unexplainable feelings, the emotions that go from fear, to devastation to determination. Only other parents who have been there and done that can relate to this. Many of us were asked, "How can you?" We just do. We have truly little choice in the matter.

If you choose to interrupt this pregnancy, all the experts have told you based upon countless tests that your unborn child's chances are less than 50%, you must endure the stigma. You wanted this baby and you chose not to have them suffer. It is not a selfish act but a selfless one. Some will state if you didn't go full-term this child doesn't count – so not true. You will also change because of this experience. Your child will never know the pain and will always be in your hearts.

If you choose continue the pregnancy and hope and pray for the best you will also have doubts and wonder if you can endure seeing your small infant go through surgery, recover and endure. If you are the mother, you will have this constant reminder moving and kicking within you. If you are the father, each time you see your partner, you will have this reminder. The thoughts of what you both will have to endure for your child and what your child will endure will not be far from either of you.

Then there are those couples who were expecting a healthy baby and their child is born and goes into repertory distress. They whisk the baby away and start intubation and assessing the condition of the infant. You may not hear anything for hours. Not knowing what is happening to your child, to this baby you have a nursery prepared for, a life planned out for and now they are taken from you. The doctors will then come to you and tell you of this birth defect which has a 50% mortality rate. Your child may be treated in the hospital you delivered or many times may have to be transported to another for treatment. You are in shock. What in the heck is a congenital diaphragmatic hernia? How did that happen? Why didn't they see it before? When can I see my child? When can I hold them? Those that had the diagnoses prior to birth at least know of the protocols and procedures that health care institutions do to attempt to save the lives of these babies.

Both will sit by the bedside and pray, hope and wonder what is next? You face the unknown, the lack of control, the overwhelming feeling of parents just to pick their child up who is suffering and ill cannot be acted upon. This isn't supposed to happen this way! Why your child? No one can give answers to that question. You go from watching the monitors to not watching the monitors to asking if they have had a good day or a good blood gas for the past hour. Sometimes you cling to just a good minute.

If you are blessed enough to have your child endure surgery, possibly ECMO and recover from both then the next hurdles are feedings and weaning the painkilling drugs they have been on since birth. This is a slow process. It takes time and patience. Many of these children due to the organs affected may have gastrointestinal reflux and due to the tubes down their throats oral aversions. You wonder how you are going to take care of this once fragile infant at home. You are warned of their lung condition being

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fragile, that they may not have the immunities other children have and must be guarded against a society full of germs. Your best friend will be anti-bacterial soap and hand sanitizers. (Next to an abundant supply of burp cloths for the reflux.)

And if you are faced with letting them go, allowing them to earn their wings, either by their choice or after being told that everything that could be done has been and there is nothing left to do. That is the worst loss, but each and every parent who has had ever to let their child go in this way will tell you, "We just knew it was time". The most unselfish act in the world is to tell your loved one, "It is okay to go." They will be out of pain, not have to endure any more but that is when your pain will immeasurably increase.

It takes courage, faith, strength you never thought you could have to endure having a child with CDH. You will be the most devastated you ever have been, you will be more exhausted both physically and emotionally than you ever have been before. You will also know that no matter what life throws at you now, it is small compared to what you have endured.

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