



10 things to do after a diagnosis

by lonnie somers

Nothing prepares you for the news of a fetal syndrome diagnosis. It is as if your child is drowning, but you are unable to jump in and try and save them. This is a very frightening time with many challenges ahead. You may feel lost, confused, angry, sad, and often hopeless. To ensure you can best handle most aspects of a diagnosis, it is best to have a plan in place. While you may feel alone, the Fetal Health Foundation is with you every step of the way. Following, we provide to you the necessary things you should ask when diagnosed.

1. You will be the #1 advocate for your baby(ies) – We rely a lot on our medical professionals to guide us and have all the answers. Truth is, when you deal with fetal syndromes (*many are very rare*), our medical professionals may not have all the answers. You are now the main advocate and need to be part of the “team” in deciding what is best for

your babies. That means learning as much as you can about the syndrome. Don’t be afraid to ask questions. No question is silly.

2. Learn as much as you can about the diagnosis – Likely when you first were given the diagnosis, you absorbed about 50% of what the doctors told you. Find reputable resources like the Fetal Health Foundation, and reach out to learn as much as you can about the syndrome. Be careful, as there is a lot of misinformation and non-credible sources. It can be hard to tell the difference, so be sure to start out with credible sites such as those of the Fetal Health Foundation, NIH, WebMD, CDC, etc. These sources can be helpful in gaining a better understanding of what you are facing, what treatments are available, and where those treatments are being performed. It is important that wherever you get your information

(*again be careful that they are credible sources*), that it is easily understood. It should be easy to understand and should explain to you any clinical terminology. It is also important to understand that while support groups can be very helpful, they cannot offer advice provided by trained medical professionals.

3. Build a support network – Our first instinct is to turn to our families for support. Likely your spouse is hurting, too and while you do need to be there for each other, you will need some outside support, as well. Understand that telling family and friends comes with a mixed bag of reactions and emotions. Some understand the gravity, yet some don’t and cannot relate, while some frankly can think you are overreacting. Realize that while our friends and family mean well, they sometimes also have a hard time knowing

the right words to say, and how to truly relate. Realize they have a relationship with you, but do not have the emotional tie, as you do, to your baby. They too can and should reach out to reputable groups to learn a bit about what your baby has been diagnosed with. You should reach out to support groups on the internet and Facebook. No one will understand more about what you are going through than others who have been or are currently going through it. My word of caution though is that while these support groups can be very helpful, you can also find yourself with everyone thinking they are an expert.

4. Build your medical circle of care – You will need generally many medical professionals involved in your care. Think of it as a circle of care around you. You are the biggest part of this circle and remember, your opinion counts in your and your baby's care. You will want in your circle your OB/GYN, Maternal Fetal Medicine specialist (*and/or perinatologist*), and an expert usually from a specialized fetal treatment center (*Fetal Health has a list of these centers on our website and the syndromes they treat*). Most importantly is that you are comfortable with your circle of care. If not, then find those with whom you are comfortable.

5. Get organized – Life as you know it is going to be on hold for a while. You will be faced with many appointments, so find a way to record appointments and more importantly a place you can write out any questions you have (*as well as the answers*).

6. Ask questions and get a second opinion – As you move up the medical chain in

expertise, it can be intimidating, but I have found that most of the experts are amazingly kind, gentle, and attentive to your care. It is important to ask many questions and it is also advised to seek a second opinion. While most specialized treatment centers may not be close to you or even in the same state, many will consult with you over the phone. Here is a list of important questions you should ask:

*What do I need to know about the syndrome?

*How long have you been treating the syndrome?

*What are the treatments you offer (*pros and cons and differences vs other centers*)?

*How many cases have you treated?

*What are the outcomes (*both at birth and down the road*)?

Most importantly, be sure you are very comfortable with who you will ultimately choose as your primary treatment center. You generally have a choice, despite where your OB/GYN or high risk doctor has referred you. If a center or medical professional doesn't want to answer these questions, that likely means they don't respect your advocacy role and we would recommend seeking someone else.

7. Deciding on treatment – Usually the window for treatment is a small. This is due to either the grave circumstances of the diagnosis (*meaning there is little time to do something*), or they want to prevent further issues to the baby and need to act fast. We cannot stress enough the importance that you are part of the decision of what to do. Be sure you have educated yourself, that you have asked many questions, and that you are comfortable with your and your partner's decision. If you have any doubt, be sure to reach out to groups like us. The worst

situation is to do something and regret it because you were not well informed. One of our main missions is to prevent parents from second guessing and regretting. You don't want to ever have to wonder "what if?" No matter what course of treatment, the decision is yours, not that of some social media group, or friends and family.

8. Have a delivery plan – It is very common with most pregnancies that are affected by a fetal syndrome to deliver prematurely. Understand from your doctors what things they will be looking for that would indicate your baby needs to be delivered earlier than full term. Understand that if your baby is born early, what will take place, when, where and how. This could also mean a stay in the NICU (*Neonatal Intensive Care Unit*). The NICU can be intimidating, as all the babies tend to look so frail. They are stronger than you think. Almost all hospitals will allow you to tour the NICU, so take advantage of this courtesy. Become familiar with it and understand how your baby will be cared for there. Understand the types of machines your baby may be on/in and the reasons for them. This will lessen the impact of it seeming like such a scary place should your baby require a visit here.

9. Have a plan for compassionate delivery – While we wish it wasn't the case, sadly we do lose babies to these syndromes. If the syndrome is serious enough where this is a possibility, be sure you discuss with your partner and your medical team how the delivery will take place. Compassionate delivery equates to developing how you want to deliver your baby, who is there to support you, and whether or not you will want to have some pictures taken (*there are many support groups that help you in this area --- contd. pg. 45*



Makale, 1
TTTS Survivor

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such as *Now I Lay Me Down To Sleep*). Also, be sure to reach out to infant/fetal loss and bereavement organizations such as Heart Strings to help you cope.

10. Take care of yourself – This will be a very stressful time, and while there is no way to remove the emotions and anxiety, you need to be sure you are taking good care of yourself. Be sure you are eating nutritious meals, as eating lean sources of protein, healthy fats and complex carbs can help your baby be stronger during the syndrome. Eating well will also help keep you strong under the circumstances. Try to do some “normal” things like going shopping, watching a funny movie, going for walks (*assuming you are not on any restrictions*), etc.

No one should ever have to go through a fetal syndrome, but they do and will. Understanding and using these tips will help make you the strongest advocate for your baby(ies) and help you understand what you need to do to ensure the best possible outcome.



Pratley, 2
Cleft Palate Survivor

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