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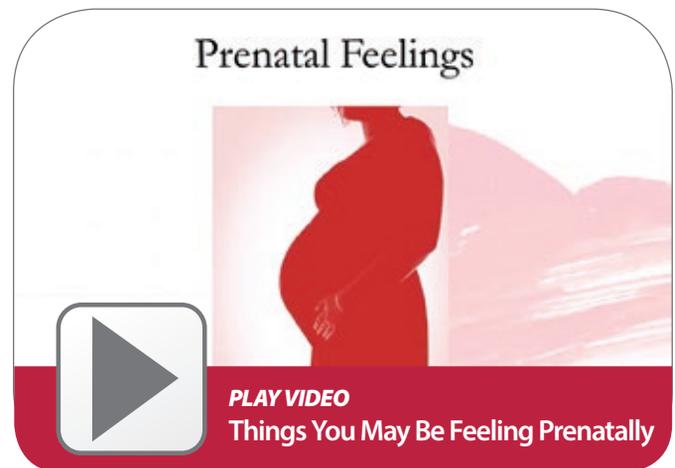
Things You May Be Feeling After a Prenatal Diagnosis

Congenital heart defects are the most common birth defects in the U.S. About 1 in every 110 babies will be diagnosed with one or more heart defects, but nothing can prepare expectant parents for hearing that there is something wrong with their baby's heart. If the child will need surgery or other medical procedures either before birth or soon after, the news becomes even scarier.

The diagnosis of a heart problem will bring questions, concerns and many complicated feelings. Some of these feelings — grief, anger, fear, guilt and confusion — are described in detail in the [Things You May Be Feeling](#) section of this Mended *Little* HeartGuide. There, you'll also find helpful tips for coping with these emotions. In this section, we will address issues that are unique to parents who are coping with a prenatal diagnosis.

Lack of “Normal” Pregnancy Feelings

Pregnancy is usually a time of excitement and joyful expectation, but after your unborn child has been diagnosed with a heart problem, you may feel less — or even none — of the enthusiasm and positive emotions typically associated with pregnancy. You might even find yourself trying not to get too attached to a child who may not survive. It's not uncommon for expectant mothers of children with CHD to refuse to have a baby shower because they can't bear the thought of having gifts for a baby who might not come home. When the pregnancy becomes visible, they may feel fear and sadness when people ask about the baby rather than joy. It can be difficult to shake these feelings.



Bear in mind that most babies with CHD do well and go home to their families. Many babies with severe heart problems end up going home and doing “normal” baby things. Avoiding the fun and joy of expecting a child will not make it less painful if the worst does happen, so as much as possible, enjoy the pregnancy as you would if you were having a baby without a heart problem. When you begin to feel fear or sadness, remind yourself that Mended *Little* Hearts is full of kids, teens and even adults with CHD who are living happy and healthy lives.

Guilt

Most parents feel guilty when their unborn child is diagnosed with a heart problem. There are many reasons for this guilt, including the idea that they may have done something to cause their child's CHD, and several of those reasons are described in the [Things You May Be Feeling](#) section of this Guide.



Expectant mothers believe that they should be happy during their pregnancy and may feel shame and guilt when they feel sad or fearful instead. They may dread their baby's birth because they know that it will not be the experience they had hoped it would be — especially if the baby will need surgery. Pregnant mothers may feel anger or resentment toward the child or situation, which leads to more guilt. They may also worry that their negative emotions are somehow harming their unborn child.

These feelings of guilt are very normal, but it is important to try to not let them overcome you. Pay attention to the things you are saying to yourself. Would you say those things to your best friend? Treat yourself with kindness and compassion. You are going through trauma, and you are human. Some negative feelings are expected. When the feelings occur, allow them to pass through you and then focus on what you can do to prepare for the arrival of your baby. Don't spend time around people who feel sorry for you or who want to dwell on your child's heart problems. Ask friends and family to think of your baby as healthy and strong and to talk to you about normal baby things rather than about his or her CHD.

Fear

Fortunately, when you find out about your baby's heart defect before he or she is born, you will have more time to educate yourself and prepare than a parent who is faced with an unexpected emergency situation after the birth. Unfortunately, the early diagnosis leaves a lot of time for you to develop fear and anxiety about the birth and any upcoming surgeries. After diagnosis, the pregnancy can feel very long and frightening. You may imagine any number of terrifying scenarios; remind yourself that these are only in your imagination. Start envisioning a more positive but realistic outcome instead. Picture your child crawling, walking or even heading to school.

The reality is that you can't predict the future, so try to focus on what you can control. Spend your time preparing and educating yourself. The more you understand what to expect, the more in control you'll feel. Don't be afraid to ask questions, get tours of the hospital and talk to other parents who have experienced what you're going through. Find out what resources are available in your community to help you care for your child. You may want to visit the cardiac unit at your local hospital, but be cautious. On one hand, it may make you feel better by eliminating some of the unknowns and giving you a better idea of what to expect. On the other hand, seeing babies and children in an intensive care setting could frighten or overwhelm you as you begin to visualize your baby in that situation.

Disappointment

Let's face it, this birth experience is probably not going to be the one you wanted. Most expectant mothers imagine their labor and birth experience as an exciting and happy time when they will get to meet and bond with the new life they brought into the world. When your child has a heart problem, your labor may need to be induced at a certain time and you may even need to have a cesarean section. You may not be able to do some things you expected to do, like hold your baby and feed him or her after birth. It's not fair that this happened to you,, and while your experience may not be the one you wanted, the key is finding things you can do to make it as pleasant as possible given the circumstances. To do this, you'll need to ask a lot of questions at the hospital where you'll be delivering and where your baby will have surgery. (See the [Preparing for Birth](#) section in this guide for some sample questions.) It will also require a lot of support from your friends and family.



Envy

Envy is seen as a negative emotion, so many people don't want to admit that they feel it, but most of us experience it at some point. It is not uncommon for parents of babies who have been diagnosed with a heart problem to envy other expectant parents. After all, they are blissfully expecting a healthy newborn while you are burdened with the knowledge that your child will face immediate health issues. When other mothers complain about their pregnancy, you may feel like they are taking their healthy babies for granted. These feelings are normal, but it's important not to hold on to them. Let them come and then put them out of your mind. The reality is that you don't have any way of knowing what those other parents will face during their child's lifetime. Everyone has their own journey. Their journey is not yours.

Become a member of Mended *Little* Hearts.

If you do not have a Mended *Little* Hearts group near you, you can still join Mended *Little* Hearts as a Member At Large to receive emails and news about Mended *Little* Hearts activities, webinars, educational materials and resources for families. There is no cost to join and the information you share is always kept private. You can join by visiting the [Mended Little Hearts website](#) or calling 1-888-HEART99 (1-888-432-7899).

During Pregnancy

Congratulations on your pregnancy! This should be an exciting time of anticipation and preparation, but we know how easily fear can override your excitement after your baby has been diagnosed with CHD. Many families describe the prenatal diagnosis as both a blessing and a curse. They miss out on some of the excitement and joy of a typical pregnancy, but have the time to better prepare themselves and family members to welcome a baby with a special heart. We hope that the following tips help you continue to enjoy your pregnancy while preparing to meet your son or daughter:

Fetal Cardiology Appointments

In most instances, expectant mothers will continue to see a fetal or pediatric cardiologist for monitoring throughout their pregnancy after their baby has been diagnosed with CHD. The frequency of cardiology visits depends on the baby's diagnosis, gestational age, other medical issues and the mother's health. These visits typically include a **fetal echo**, which is an ultrasound that looks specifically at the heart. (Learn more about fetal echos in the [Common Prenatal Tests](#) section of this Mended *Little HeartGuide*.)

OB/GYN Appointments

It is important for mothers to continue to attend regular OB/GYN appointments throughout their pregnancy. The responsibility of the OB/GYN is to monitor maternal health during pregnancy. In some instances, the OB/GYN will work with a maternal fetal medicine specialist or perinatologist who monitors fetal growth and wellness. In other cases, the maternal fetal specialist may recommend an **amniocentesis** or other tests to assess the baby's chromosomes before delivery. (Read more about amniocentesis in the

[Common Prenatal Tests](#) section of this Mended *Little HeartGuide*.) As mothers head toward the end of their pregnancy, the OB/GYN or maternal fetal specialist may suggest specialized monitoring called a non-stress test or monitoring that includes ultrasound and heart rate monitoring. In most cases, this is a precautionary measure to assure that the baby is doing well in the womb. (Learn more about the **non-stress test** in the [Common Prenatal Tests](#) section of this Mended *Little HeartGuide*.)

Questions About Delivery

There are many questions you can ask to prepare for your baby's birth. It is a good idea to prepare these ahead of time. (Use the [Questions and Answers Form](#) in this Mended *Little HeartGuide*.) It may also be helpful to bring a trusted friend or family member to take notes. Parents and caregivers may be so caught up in the emotions of the delivery, that they miss key information. Your baby's fetal cardiologist and your OB/GYN team may have to work together to answer your questions. Here are some questions to consider:

- **Where will I deliver my baby?**
In some cases, you will be able to deliver in the hospital you would normally use. Be sure to deliver in a location that is equipped to deal with emergency situations, in case one should arise. Some parents may need to change their delivery hospital to ensure that their baby receives the specialized care that newborns with CHD may require, including a heart surgery or cardiac catheterization procedure. In some cases, your baby may require transport to a specialized hospital. If he or she will need surgery in another city or state after birth, know how your son or daughter will be transported.



- **How will I deliver my baby?**
Many women can deliver vaginally, despite their baby's heart condition, but it is important to discuss your options and preferences with your fetal cardiologist and OB/GYN. Sometimes, your labor will need to be induced to best prepare for your baby's surgery or other procedure, but induction is only done when medically necessary. **Recent studies** show that the chance of complications is higher when labor is induced, so it is best to avoid this if possible. There are instances where you will need to have a cesarean section. This may not be your first choice of delivery method, but your child's doctors would not choose it if it weren't necessary for the health of you or your baby.
- **What will happen after delivery?**
You may want to ask about the time that you and your baby will have together following birth. Find out whether you will be able to hold your son or daughter after delivery. Even if you can't, you can ask to see your baby before they take him or her out of the room. The ability to see and hold your baby immediately after birth will depend upon your baby's diagnosis and delivery plan. Speak with your cardiologist about the implications of your child's diagnosis on breastfeeding, circumcision and vaccinations.

Preparing for Birth

After receiving a prenatal diagnosis of CHD, parents may feel overwhelmed when preparing for their child's birth. In addition to the regular preparation activities, there are unique considerations for parents who are expecting a baby with heart problems.

Familiarizing yourself with the hospital where your baby will have surgery will help you feel more comfortable when you get there, and speaking with the medical professionals who will treat your child can help answer many of your questions. In addition, making plans ahead of time to address the needs of siblings, manage work responsibilities and understand the resources available to you and your child can help minimize your stress after your child's birth. Here are some things to do before delivery:

The Hospital

Ask for a tour of the hospital and unit(s) where your baby will receive care. This will help you familiarize yourself with the resources that will be available for you and your baby after delivery. You will also be able to better anticipate what you'll need to bring to the hospital. During the tour, you may want to ask about:

- **Sleeping arrangements for parents and families:** Discuss the hospital's policies on visitation and overnight stays by parents. Although many hospitals now allow (and welcome!) parents to stay overnight with their baby, this is not the case in every hospital.
- **Hospital visitors:** Most hospitals have policies regarding sibling and non-family member visitation. Familiarize yourself with these policies before your baby arrives so that you can prepare your family members and friends.
- **What to bring to the hospital:** Speak with your



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Preparing for Birth—Questions to Ask

social worker or nurse about what to bring to the hospital. Pack two bags: one for you and one for the baby. Hospital policies vary regarding what is provided and what you can bring so find out what is acceptable ahead of time. Common items to include for your baby are booties, mittens, front-snap onesies, small stuffed animals and family photos. For parents, consider comfortable clothing, shower shoes, toiletries, nursing bras, phone chargers, a journal and a good book. (You may also find the [Packing List](#) in this Mended *Little Heart*Guide helpful.)

The Medical Team

Ask your cardiologist if it is possible to meet with the team who will be managing your baby's care after delivery. This team may include the surgeon, cardiologist, nurse practitioner, social worker and nutritionist. Identify a pediatrician who will provide routine care once your baby is home from the hospital. Your child's pediatrician will work with his or her cardiologist to manage your child's unique needs.

Siblings

Spend time preparing siblings for the arrival of the newest family member and for your time away from home. Think strategically with your partner, family members and friends about how to ensure that your newborn's siblings do not feel left out.

Take breaks from the bedside of your baby to spend time with your other children and have siblings make visits to the hospital. Inquire about Child Life Services at your hospital and discuss ways to prepare siblings for their first visit. (For more tips, see the [What About Siblings](#) and [Taking Care of Other Children While in the Hospital](#) sections of this Mended *Little HeartGuide*.)

Leave Benefits and Time Off Work

Familiarize yourself with your leave benefits and make a plan for how to best use your maternity/paternity leave. Find out if your employer has a donated leave policy and, if so, inquire about how to access the donated leave bank to extend your time off. For prolonged hospitalizations, some parents find it helpful to return to work earlier than anticipated in order to preserve leave for when their child is discharged. It may be helpful to speak with your employer before your child is born to discuss options such as teleworking and returning to work part-time. (See the section on [The Financial Impact of CHD](#) in this Guide for more information.)

Insurance/Health Coverage

Contact your employer's human resources department to find out how to add your baby to your insurance policy. Because it can be easy to overlook this in the days immediately following birth, make a plan to complete any paperwork ahead of time. (For more information, see the section on [Navigating Insurance](#) in this Mended *Little HeartGuide*.)

Childbirth Preparation Classes

Explore birth and childcare classes that are available in your community. Popular courses include birth preparation, basic childcare, infant CPR and infant massage. If you would feel uncomfortable in a traditional birth/child care class due to the medical needs of your baby, speak with your social worker or nurse about alternative options, including private sessions.

Breastfeeding

If you plan to breastfeed, research lactation consultants through your hospital. If your baby will be hospitalized for any length of time, look into buying or renting a quality breast pump and learn how to use it. (For more information, see the [Nutrition](#) section of this Guide.)

Family Members

Research options on how to keep your family members and friends up to date on your baby's health. Some families choose Facebook, [CaringBridge](#), [Care Pages](#) or other online options. Others designate a point person (usually not Mom or Dad!) to handle updates and questions. Making a plan ahead of time will make it easier for you to focus on your baby after delivery.

Information and Binders

It is never too early to start a medical binder to store information about your baby's special heart. Use it to organize drawings, printed information and business cards of your baby's care team. (Instructions on [Creating a Binder](#) are available in this Mended *Little HeartGuide*.)

After Delivery

The period immediately after birth can be physically and emotionally exhausting and you may feel pulled in many different directions. It is vital that you take care of yourself in order to provide the best care for your baby. Please refer to the [Taking Care of Yourself](#) section of this Mended *Little HeartGuide* for tips on how to do this.

For helpful information about a hospital stay with your child, see [Part 3 of this Mended Little HeartGuide](#).



Common Prenatal Tests and Procedures

Fetal Echocardiogram (Fetal Echo)

A fetal echo is an ultrasound test that uses sound waves to create an image of your baby's heart to see how it has formed and how it is working. It can also show blood flow through the heart. This test is typically conducted around 20 weeks into pregnancy and may be used to diagnose CHD, to confirm a diagnosis that was made during an obstetrical ultrasound and get more information about your baby's heart. If your family is at high risk for congenital heart disease, or if you already have one child with CHD, a fetal echo may be used to determine if there is a heart defect in your baby.

A fetal echocardiogram is usually performed by an ultrasound technician but may also be conducted by a

fetal cardiologist or perinatologist (maternal fetal medicine specialist). It is painless and does not involve radiation, so it cannot harm you or your baby. The technician will place a transducer, like a wand, with gel on it onto your belly. The gel helps transmit the sound waves (you won't hear them because they're too high pitched for human ears to detect). The probe will be moved around to get pictures of your baby's heart. Sometimes, it may be left in one location for a few minutes to get an image. The images are usually shown on a screen, but unless you're trained to read echoes, it is very difficult to figure out what you are looking at. Some technicians will show you the valves, atria, ventricles and other parts of your baby's heart but they typically cannot tell you anything about your son or daughter's CHD. You'll get that information after a cardiologist has reviewed the results.

The fetal echo can be a long test — lasting up to two hours — so make sure you've had something to eat and arranged to have someone care for any other children you have. You don't need to do anything to prepare for a fetal echo, but bring your medical records with you. Sometimes, you'll have an appointment to get the results right after the test has finished. Other times, it will take a few days or a week to get results. If you can, bring someone with you who can take notes. Don't forget to ask any questions you can think of. If you think of a question after the appointment, call back and ask to make sure you have the information you need. It's important to note that not all heart defects and/or heart disease will be diagnosed during a fetal echo, so the diagnosis may change after your baby is born as his or her blood flow changes.

After CHD is diagnosed, your baby's cardiologist will likely want to perform more than one fetal echo during your pregnancy so that they can prepare for your baby's birth. You may feel like you are getting new information at every appointment, but that is probably just because it is hard to take everything in at the first visit. List your questions before each appointment. (Use the [Questions and Answers](#) form in this Guide.)

Non-Stress Test

A fetal non-stress test is a test done by the obstetrician that monitors a baby's heart rate and allows doctors to see whether your baby's heart rate pattern is normal and varying with movements. This information helps the doctor determine whether there are any problems that need to be addressed. This test is usually done once or twice a week after 26 weeks of pregnancy. It is non-invasive and there are no risks.

You don't need to do anything to prepare for this test, but if you eat a little something or drink some juice right before it, your baby may be more active, which can help the doctor get better information. If your baby is asleep, you may have to schedule another non-stress test sooner than planned.

The non-stress test is usually done at your obstetrician or maternal fetal medicine specialist's office. You will be on a reclining chair or bed and belts/bands will be placed across your belly. These have monitors attached that record information. You may be asked to press a button when your baby moves. It takes around 20 minutes but may take longer if your baby isn't moving much. You might hear your baby's heart rate and it may speed up and slow down several times during the test. Usually, you will not need additional tests or monitoring at that time unless the results cause concern.

Amniocentesis

Amniocentesis is a test used to check for chromosomal abnormalities like Down syndrome. It is also sometimes done to determine whether a baby's lungs are developed enough to be born.

During amniocentesis, a small amount of amniotic fluid (the water-like fluid that surrounds your baby before he or she is born) is removed with a thin, hollow needle. The spot on your belly where the needle is inserted will be cleaned before the procedure, and you may get a local anesthetic to relieve discomfort. An ultrasound will be performed at the same time so that the doctor can see where to place the needle in the uterus without getting too close to your baby. The amniotic fluid is then sent to a lab for testing. Your doctor will tell you when to expect the results.

You may have some cramping during the amniocentesis and for a few hours afterward. You should rest for the remainder of the day after the procedure. Your doctor will tell you if you can take any medication for discomfort. Have your spouse, a relative or a close friend drive you to and from your appointment. This test can be stressful, and you'll want someone there to support you.

There are some risks with amniocentesis, but complications are rare. The risk of miscarriage is less than 1 percent, but be sure to ask your obstetrician about risks and complications.



Frequently Asked Prenatal Questions

Important: The questions and answers below address some common concerns that parents and caregivers have about the birth of a child with CHD, but always turn to your medical team for questions about medical issues.

Q: I feel like I did something to cause my baby's CHD. What did I do wrong?

A: Some congenital heart defects may be linked to genetic or environmental factors, and certain things that mothers do or are exposed to may increase the likelihood of having a baby with CHD, but that doesn't mean you did anything to cause your child's heart condition. Most cases of CHD have no known cause, so no one can say that anything you did or did not do caused your child's heart problem. Let go of the guilt.

Q: I am having trouble bonding with my unborn baby. Is this normal?

A: It is not at all uncommon. When parents hear that their baby has CHD, they may distance themselves from the child in an attempt to protect themselves from the unknown. Some parents feel that they would not be able to bear it if they bonded too much with the baby and then he or she did not survive. The truth is, there is nothing you can do to mentally or emotionally prepare for the loss of a child. There are, however, some things you can do to help you start bonding with your baby. Learn his or her gender, start a journal about your baby, write letters to your son or daughter, pick out a name and use it when thinking of or referring to your child. If you are still struggling, your obstetrician can recommend someone for you to talk to about your feelings.

Q: Even after it was explained, I don't understand my baby's heart defect. What can I do?

A: Ask your cardiologist or surgeon to explain it again, draw a picture or have someone else explain it to you in another way. If you want to understand the heart defect, your medical staff will go out of their way to help you. Don't be afraid to ask. Sometimes people who deal with hearts all day, every day, forget that most of us don't understand medical jargon. Keep asking until you get the information you want and need. Also, ask them to refer you to reliable online or printed information that will help you learn more.

Q: My doctor called my baby's heart defect "rare." Does that mean there is no hope?

A: Even though congenital heart defects are the most common form of birth defect in the U.S. — affecting about 1 in every 110 babies — there are 35 commonly recognized types of congenital heart defects and variations on many of them. Because of this, nearly every type of heart defect can be classified as "rare." The good news is there is treatment and/or surgery available for most types of CHD. Talk to your baby's cardiologist or heart surgeon before giving up hope. Get a second opinion to be sure you have as much information as possible. (Also refer to the [Making Health Care Choices](#) section of this Mended *Little HeartGuide*.)



Q: Can any procedures be performed to help my baby before he or she is born?

A: As there are more and more medical advances in the area of CHD treatment, fetal catheter intervention possibilities are becoming more common, but they are not without risk and are not available at every hospital. Talk to your baby's cardiologist or surgeon about which prenatal options, if any, are available for your baby and what the risks are. (For more information, refer to the **Making Health Care Choices** section of this Mended *Little HeartGuide*.)

Q: What can I do during my pregnancy to help the baby? Are there things I should or should not do in terms of physical activity, stress and work?

A: This is a question to ask your obstetrician, but many women carrying babies with CHD have pregnancies that are no different than any other pregnancy. Get good prenatal care. Eat well. Get enough rest. Do things to relax your mind and body. Be sure to visit your obstetrician and fetal cardiologist regularly. They can tell you whether there is anything you need to know, do or avoid to take the best care of yourself and your baby.