

Supporting Your Heart Journey: A Guide for Families



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Table of Contents

HEART TO HEART	3	NEXT STEPS	25
QUESTIONS YOU MAY HAVE	5	How Will This Affect My Delivery Plan?	26
The Diagnosis	6	My Hospital Admission	27
Why Did This Happen to Me?	8	ASKING FOR HELP	29
How is My Baby's Heart Different?	10	How Can I Get the Support I need?.....	30
WE WILL BUILD A TEAM AROUND YOU	13	ONLINE RESOURCES	33
Health Care Teams and Roles	14	Gathering Information about Hospitals, Outcomes	34
Medical Genetics	19	Learning About Your Child's Diagnosis	36
Will CHD Impact My Child's Learning and Development?	21	General information about CHD, logistics, emotional impact	37
THE DECISION TREE	22	Programs that offer mental health care/childcare packages/financial support	38
Will My Baby Survive? What Are My Options?	23	Parent Stories	39
		Connect With Other Parents	40
		Grief and Bereavement Support ..	42
		En Espanol	43

Heart to Heart



Heart to Heart

Modern healthcare can tell you many things about your unborn baby. But being told your unborn baby has a problem with his or her heart can be shocking, frightening and unexpected. Your healthcare team recognizes this as a very emotional and upsetting time. We are here to extend our support to you.

You may be asked to consider choices for your pregnancy or treatment for your baby, even before your baby is born. Sometimes there is no clear answer. Choices about your pregnancy are influenced by family circumstances and supports. For some families, talking with a spiritual care provider, a Social Worker, or a Psychologist can be helpful. This booklet is designed to help you understand your baby's heart and the options and possibilities for both you and your baby. It also contains practical information you may find useful about our service and other resources available to you. We are committed to providing you with the information you need to feel supported during this difficult time.

Pregnancy is usually a time of

Excitement and anticipation

Plans and preparation

Hopes and Dreams

Now this precious time has been interrupted by

Concern about your baby's heart

Waiting for tests and information

Worry and anxiety

Knowing but not knowing is

Experiencing uncertainty

Balancing concerns

Rethinking your dreams

Questions you may have



The Diagnosis

There are many different heart defects that can affect the baby. These are known as Congenital Heart Defects (CHD). Some are minor defects in the structure of the heart which may not need treatment at all. Other, more serious defects can often be corrected with an operation. Very severe congenital heart defects sometimes require several operations so that your baby may live with the best quality of life possible despite the fact that there may not be a cure. In addition to structural defects, some babies have a problem before birth with the function or pumping of the heart muscle (cardiomyopathy) or with their heart rhythm.

Some Commonly Asked Questions:

What is a prenatal diagnosis?

Prenatal means “before birth.” A prenatal diagnosis is an illness or problem that is discovered about your baby’s health before they are born. You might also hear it referred to as “antenatal” or “fetal”. All of these mean the same thing: before birth.

What is a congenital heart defect (CHD)?

Congenital is the word used to describe health problems that are present at birth. The heart is completely formed by the 8th week of pregnancy. If the heart has not formed properly, the baby will be born with a congenital heart defect. You may also hear CHD referred to as a lesion, abnormality, or malformation. Heart defects can range from a tiny hole that requires no treatment, to structural problems that are not compatible with life.

What causes congenital heart defects?

There is no single cause for CHD. For the majority of CHD, no one knows what caused them. You may hear “multifactorial causation” regarding your baby’s heart defect. This means that no one particular thing caused the problem, but rather a combination of possibilities like certain genetic and environmental factors that occurred at the same time.

Six to eight of every 1,000 babies have a heart defect (less than one percent of all babies born). About one third of these babies have a severe cardiac defect requiring medical or surgical treatment.

If you have a close family member with CHD, the chance of having a baby with CHD increases from one percent to about three percent and in some cases higher.

Because heart defects mostly happen by chance, or when different factors occur at the same time, the majority of parents with a baby who has CHD are healthy and the diagnosis is unexpected.

What is a fetal echocardiogram (echo)?

Fetal, or fetus, refers to a developing baby. An echocardiogram (echo) uses ultrasound to take pictures of the heart. Taking ultrasound pictures of a developing baby's heart is called a fetal echocardiogram.

Having a fetal echo feels similar to having an obstetrical ultrasound. Instead of looking at the whole baby, it looks just at the baby's heart. A fetal echo shows the parts of the heart (structure), how the fetal heart is working (function), and how it is beating (rhythm). Heart problems can be diagnosed as early as the first trimester, but a more detailed evaluation is always encouraged in the second trimester.



A specialized heart doctor called a Fetal Cardiologist will closely review the fetal echo and will talk with you about what the echo showed. The doctor will explain what this means for you and for your baby. You will probably have more fetal echoes throughout your pregnancy to monitor the baby.

Who can answer questions about the baby's heart diagnosis BEFORE they are born?

Before your baby is born, the Fetal Cardiologist will be there to answer your questions about your baby's diagnosis.

Who can answer questions about the baby's heart diagnosis AFTER they are born?

After your baby is born, a Pediatric Cardiologist (a specialist in children's congenital heart disease) or a Neonatologist (a specialist in managing newborns with intensive care requirements) will be on your team. They can help to answer questions as you go along.

Who can answer questions about my pregnancy?

Your family will have the support of a Maternal Fetal Medicine (MFM) Specialist (a specialized doctor in high-risk pregnancy). Your Family Doctor and/or Obstetrician will still be involved in your care.

Checklist of Common Questions

Use this checklist to guide you as you discover the answers to some of your initial questions. You may write in the page number where you find the answers, or you can add in your own questions that haven't been answered yet.

What does this diagnosis mean for my baby before and after birth?

What other problems could my baby have?

What are the options for my pregnancy?

Who are the doctors that will tell me about the options for me and my baby?

How frequently will I have follow-up appointments?

How long does a fetal echocardiogram appointment usually take?

Do I have any activity restrictions during my pregnancy?

Can I still work?

Other questions I have:

Why did this happen to me?

People often wonder if there is something they did to cause the problem, or if they could have done something differently to prevent it. The vast majority of congenital heart defects are completely unexplained. They often affect families who are otherwise completely healthy. This means that it is very unlikely that the problem could have been prevented. Even heart problems that are linked to genetic or chromosomal disorders do not happen because anyone did anything wrong.

What are the chances of the diagnosis being wrong?

Often parents hope that the diagnosis is wrong and maybe their baby doesn't actually have a heart problem. Once a diagnosis of major CHD is made, your care team is certain that there is a structural defect in your baby's heart. In the vast majority of cases, the diagnosis made prenatally is completely correct and will not change. A scan performed directly on a baby after they are born can sometimes give more detail about the condition, but the diagnosis itself rarely changes. If there are any doubts about whether or not a diagnosis is complete, this will be explained to you by your doctor at your fetal echo appointment.

Will this heart problem get better by itself?

The fetal heart is fully formed by around the 8th week of pregnancy. This means that when a problem with your baby's heart is found, it has already been there for some time. Unfortunately, it is uncommon for fetal heart problems to get better on their own. Usually they stay the same and in some cases, sadly, they can get worse. If your doctor thinks there is a chance that your baby's heart condition could improve, they will tell you about this. They will also discuss the chances of the heart condition becoming worse, and what this would mean for the pregnancy.

Will this happen again?

The chance that a CHD will happen again in another pregnancy is usually quite low. Your doctors or genetics team can tell you the risk in your particular case. In general, if you have had one child with a heart abnormality, the risk of having a future baby with a heart abnormality is around three to five percent. This means that the vast majority of families will not have heart problems come up again. When planning future pregnancies, it is always important to discuss your risks, and ways to stay healthy, with your doctor, genetics professional or other healthcare provider.

Are my other children okay?

Your other children will have been examined by your pediatrician or family doctor and probably other doctors on many occasions. It is extremely likely that, if your other child's examination has been normal, everything is absolutely fine. If a doctor is worried that there could be a risk of your other children having a heart problem, they will let you know and arrangements will be made to have your other children assessed by a cardiologist.

How is My Baby's Heart Different?

In order to better understand your baby's heart, it helps to understand the structure and function of a normally developed heart.

The normal heart has:

Four chambers

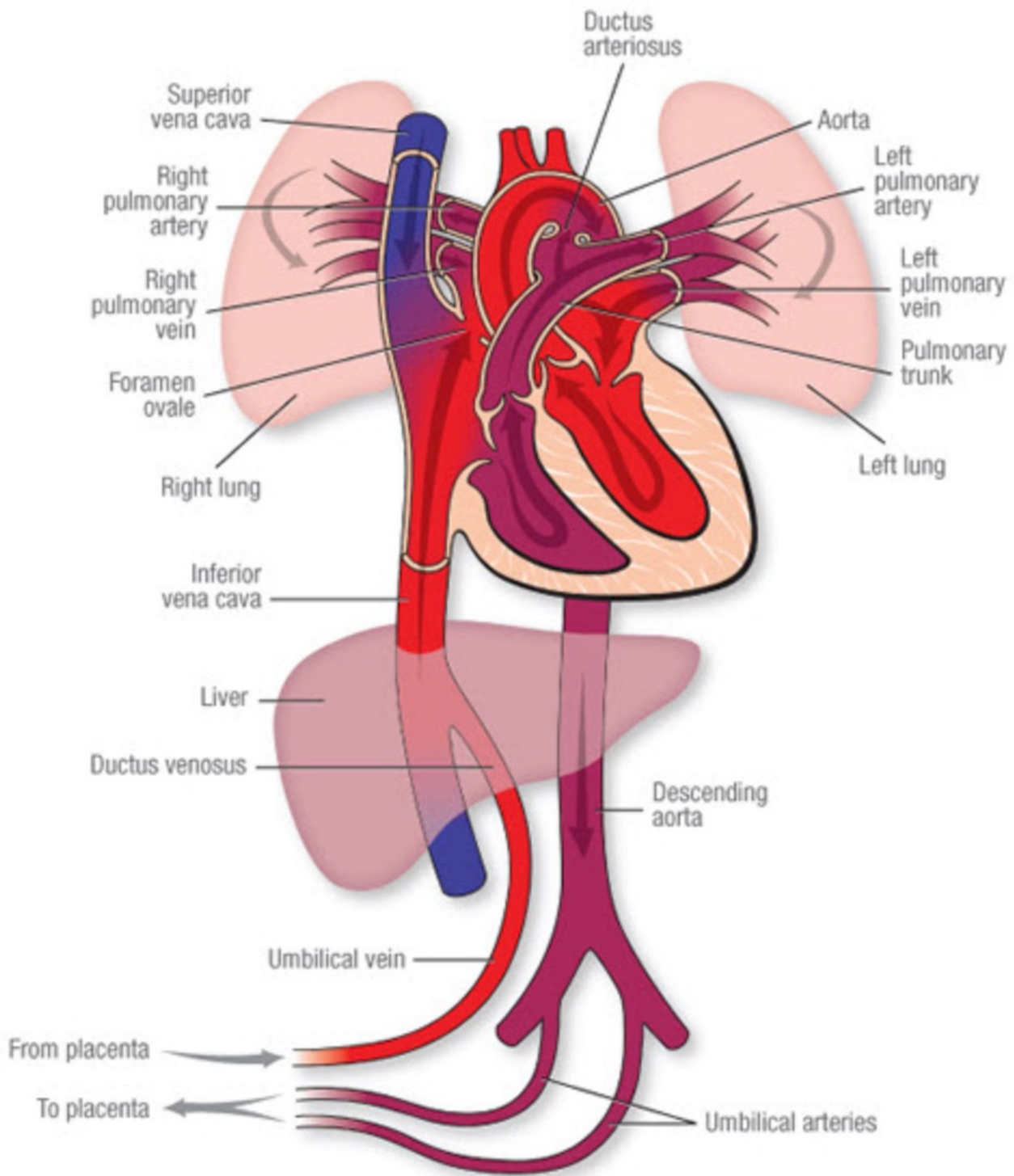
- Two upper chambers (right and left atria).
- Two lower pumping chambers (right and left ventricles).

Four valves to keep blood moving through the heart in the right direction


- Two inflow valves called the mitral valve and the tricuspid valve. These control the direction of blood flow from the atria to the ventricles
- Two outflow valves called the aortic valve and the pulmonary valve. These control the direction of blood flow out of the ventricles.

Two great arteries

- The pulmonary artery carries blood to the lungs for oxygenation.
- The aorta carries oxygen rich blood to the body.



Your Doctor may use this space to draw the structure of your baby's heart:

A close-up photograph of a doctor in a white lab coat holding the hand of a pregnant woman. The doctor is wearing a silver watch and glasses. The woman is wearing a pink top. The image has a warm, orange-tinted overlay.

We will build
a team
around you

Health Care Teams and Roles

Fetal Cardiology Team:

Fetal/Pediatric Cardiologist

A Fetal/Pediatric Cardiologist is a doctor who has taken extra training in caring for fetuses and children who have heart problems. The Fetal Cardiologist reviews all the fetal echocardiograms. If the pictures obtained do not provide enough information, they may take more pictures to clarify what they see on the fetal echocardiogram. The Fetal Cardiologist will tell you about your baby's heart diagnosis, your options regarding your pregnancy, and what treatment options are available before and after the baby is born (also called counseling).

Pediatric Cardiothoracic Surgeon

The cardiovascular surgeon performs surgery for pediatric heart disease and their team provides wound care after surgery. They will meet with you to explain the technical aspects and risk of any surgeries your child needs.

Fetal Cardiology Fellow

A Fetal Cardiology Fellow is a Pediatric Cardiologist who is taking extra training under the supervision of a Fetal Cardiologist so that they can care for fetuses with heart diagnoses. A Fetal Echo Fellow may perform the fetal echo, which will be reviewed by the Fetal Cardiologist in charge.

Fetal Cardiac Sonographer

A Fetal Cardiac Sonographer is a person who is trained in ultrasound imaging and, in particular, taking ultrasound pictures of a fetus' heart. They will perform the fetal echo and then the Fetal Cardiologist will review the pictures and sign off the report. Fetal Cardiac Sonographers can take images of the heart, but they do not make the diagnosis.

Fetal Cardiology Nurse Coordinator/Nurse Practitioner

This is a nurse who will provide education and support to you as you learn about and adapt to your baby's heart condition. The nurse will help coordinate your care with other members of your care team and will be a great contact person for any of your questions or concerns.

Health Care Teams and Roles

Fetal Cardiology Team:

Research Nurse Coordinator

This is a Registered Nurse who assists with coordination of the research projects in the Fetal Echo Clinic. The Research Coordinator will discuss the active research projects in detail with you and, if you are interested in participating, they will obtain your written consent. They will work with you to coordinate research related activities, exams, or follow up as required. Participating in research is completely optional and will not affect the medical care you receive.

Maternal Fetal Medicine (MFM) Team:

MFM Specialist

An MFM Specialist (sometimes called a Perinatologist) is a doctor who has extra training in high-risk pregnancies. A pregnancy is classified as higher risk when either the mother or the baby has a condition that requires extra monitoring. You will see an MFM Specialist in the MFM Clinic for management during your pregnancy. You will continue to see your Obstetrician, who will coordinate the plans for your delivery with your entire team.

MFM Nurse

The MFM Nurse is a nurse-patient liaison for all high-risk patients being followed closely during pregnancy in the MFM Clinic. The MFM Nurse works with the entire MFM team to coordinate your care and is a resource person for you and your family.

Fetal Sonographer

The MFM Sonographer is an ultrasound technologist who takes complete obstetrical ultrasounds (not just the heart) in the MFM Clinic for fetuses with high risk factors. In fetuses with heart defects, ultrasounds will be performed to determine whether any other organs or structures have differences or abnormalities as well. As your pregnancy progresses, ultrasounds will be done to monitor the growth and well-being of your baby.

MFM Clinical Nurse Care Coordinator

MFM Receptionist

This receptionist works in the MFM Clinic and will assist you with your bookings for obstetrical ultrasounds in the MFM Clinic.

Other Care Team Members You May Meet

Neonatologist

A doctor who has specialized training in the diagnosis and treatment of disorders in newborns.

Social Worker

Social Workers are a part of the healthcare team and your well being is their concern. They can help to address logistical concerns about things like arranging local housing prior to and after delivery if you live far away from the hospital. They can connect you to community resources and assist with practical issues such as transportation and applications for funding support. They will get to know you and assess your family's needs so they can advocate on your behalf. If you are experiencing significant mental health problems like anxiety or depression, they will help you find the level of mental health care you need.

Reproductive Mental Health Therapists

This is a team of Psychologists who can provide counseling and support to families who have a heart diagnosis in their fetus. See resource section for more details about how this team can help you and how to contact them.

Palliative Care Team

Specialized pediatric palliative care teams focus on supporting families who are considering comfort care or palliative care as the plan for their baby. You can meet with this team to learn more about comfort care before deciding if comfort care is the right option for you. If you choose comfort care, this team will work with all your child's other healthcare providers (e.g., pediatrician, specialists, home care) to give your child and family an extra layer of support. Children and their families may get support from the palliative care team for many years, along with their other medical care. Palliative care teams are made up of experts who offer:

- Support when a child's CHD is first diagnosed
- Help making decisions and planning for care
- Care for a child who is dying at home, in hospital, or at a hospice
- Grief support for parents who have lost a child

My Prenatal Care Team

(You may meet more than one person from each specialty)

My fetal cardiologist is: _____

My fetal cardiology nurse is: _____

My MFM specialist is: _____

My MFM nurse is: _____

My local obstetrician is: _____

The obstetrician who will deliver me is: _____

My genetics counselor or specialist is: _____

My social worker is: _____

Other support team members: _____

Medical Genetics

Some heart problems can be associated with genetic abnormalities in a baby. Sometimes a genetics workup may reveal other issues that may arise related to a genetic condition. If your doctor is concerned that there may be a chance your baby has a genetic disorder underlying their heart defect, then you will be referred to the genetics team to discuss.

The overall role of the genetics team is to:

1. Explain, if possible, why a heart problem has occurred in your baby.
2. Help you to understand if there are other expected health or learning issues for your baby.
3. Help you to understand the chance of this happening again in another baby, another family member, or your baby's children.

Medical Genetics Team

Genetic Counselors	Health professionals who specialize in explaining genetic testing and disorders to families
Medical Geneticist	Doctors who specialize in diagnosing, counseling and researching rare disorders
MFM Specialist	The obstetricians who can do the procedure to obtain the baby's DNA if needed

Why is genetic testing being offered?

Some CHD can be linked to a genetic disorder. Sometimes a genetic disorder might be suspected when there is a family history of CHD or other abnormalities. Other times, your baby's diagnosis is the first time the genetic problem has happened in a family. If your baby has CHD, you may have the option of doing genetic testing for the baby.

The chance of finding a clear genetic cause is higher in some cases than in others. The probability of identifying a genetic cause in your baby will depend on what type of CHD they have, any other features seen on ultrasound, and any other medical information or family history that is present. Your Doctors will help you understand the specific chance of finding a genetic link in your situation.

How is genetic testing done?

If you decide to do genetic testing, a sample of the baby's DNA is needed. This can be obtained in different ways:

1. Chorionic villus sampling (CVS): a small part of the placenta is taken through the cervix or the abdominal wall.
2. Amniocentesis: a sample of the fluid from around the baby is collected.
3. Non-invasive prenatal testing (NIPT): a blood test for the mother, so there is no risk to the fetus. Speak with your Medical Geneticist or Genetic Counsellor to learn more.

Pros and Cons

There is a small risk of miscarriage or early delivery associated with some of these procedures. If you do not wish to test during the pregnancy, similar genetic testing can be done by taking a blood sample from the baby after they are born. There are pros and cons to each method of testing, and your Doctor or Genetic Counselor will discuss them with you before you decide. It is also important to make sure you understand any potential costs that you may be billed for if insurance does not cover the testing cost.

What are they testing for?

The genetic sample will be tested for different things depending on the testing method used, the type of CHD diagnosed, and any other information gathered. Samples may be tested for Down syndrome, 22q11 deletion syndrome (DiGeorge syndrome), and other chromosomal and genetic disorders. Some of the test results will come back within just a few days, but many of the tests will take weeks or even longer.

What to prepare before meeting the Genetics Team

When you meet with the medical genetics team, you will be asked about things such as:

- Other children in the family with heart problems or other health issues
- Miscarriages in the family or babies in the family who have passed away
- People in the family with intellectual disability or other developmental delay

Is genetic testing right for me?

Genetic consultation may help you to understand why this has happened and to plan for the future for both baby and family. This information might be helpful to families in different ways or at different times. Some people may find this information overwhelming, while others may find it empowering. The reason behind pursuing (or declining) genetic testing is unique for everyone. A Genetic Counselor can discuss genetic testing with you further if you wish.

Will CHD Impact My Child's Learning and Development?

Children with CHD are at risk for learning challenges. It is difficult to predict when a cardiac diagnosis will impact the learning and development of a child. It varies significantly from patient to patient and is influenced by each child's specific diagnosis, any other diagnoses they may have, and how well they recover following medical intervention.

In order to monitor learning and development as a child grows, and to connect families with resources as early as possible, you will be followed regularly by your Pediatric Cardiologist and Pediatrician. You may also be referred to other specialists to ensure young children have access to developmental and learning supports if needed.

A Follow-up Program

Many centers have some form of a follow up program for young children after neonatal cardiac surgery or other lifesaving, complex surgeries, and after heart-lung life support.

These programs:

- Assess the child's abilities as they grow
- Support young children in early development
- Encourage early intervention and education programs when needed
- Ensure the skills needed for ongoing learning and community integration are being developed
- Assist older children with school placement and learning supports as needed

Assessments are offered in developmental and neonatal follow-up clinics. Assessments are done by qualified professionals within multidisciplinary clinics. These programs typically will check motor, language and learning skills. They will take growth measurements and a health history. Physical and neurological examinations are also done.

A pregnant woman with long, wavy hair is sitting on a pebbly beach, looking out at the ocean. She is wearing a long-sleeved top and pants. The image has a teal overlay. The text "The Decision Tree" is written in white, bold, sans-serif font across the middle of the image.

The Decision Tree

Will My Baby Survive? What Are My Options?

The decision about what can be done for your baby depends on the type of heart defect your baby has. After making the diagnosis and receiving the results of any additional tests, your specialist medical team will explain the treatment options available to you.

When the diagnosis of structural heart disease is severe, and there is no opportunity for a cure, three treatment paths may be discussed:

- Medical and surgical intervention after birth
- Termination of the pregnancy
- Adoption after birth
- Comfort care

What can we do to treat our baby?

Choosing Medical and Surgical Intervention

Small holes in the heart do not require any intervention before or after birth and many close on their own within the first months to years of life. This is also true for mild valve problems.

Larger holes may require medications and a common operation to fix the problem early in life.

Complex heart defects usually require one or more operations to fix the heart or to make the circulation closer to normal. These operations may take place within the first few days, months, and years of life.

The Fetal Cardiologist will discuss all the details of each option with you.

If a surgery fails to improve the problem, or a baby does not recover well from the surgery, a heart transplant may be considered. Heart transplantation is also an option for babies and children whose heart defects are so severe that there is no medical or surgical procedure to improve the condition.

What are my pregnancy options?

Choosing not to continue the pregnancy, or choosing to continue the pregnancy and not parent the child (adoption), or choose to continue the pregnancy and not intervene after birth other than to keep the child comfortable (comfort care). When the diagnosis of a heart defect is made, the pregnant woman usually has the option to continue or not continue the

pregnancy depending on how far along she is in the pregnancy. For some parents, the knowledge that even after repeated surgery their child's heart and lifestyle will never be typical leads to a decision to end the pregnancy. These choices are both very personal. There is no right or wrong decision, but only what is right to each individual. We will never tell you what to do. We will simply give you the information that you need to make the best decision for you. We will support whatever decision you make. If you are thinking about not continuing with the pregnancy, please speak to one of your doctors about this.

What if my baby's heart is too sick to recover?

Choosing Comfort Care

For some families, choosing to let nature take its course and allowing the baby to pass away in comfort is the best decision for them. Some parents feel they cannot contemplate ending a pregnancy, but do not feel that they want their baby to go down the surgical route of treatment. In these cases, a family can choose to offer their baby comfort care to ensure quality of life and minimal pain **without correcting the underlying heart problem**. The focus of comfort care is living comfortably, even if only for a short time.

Many centers have a Palliative Care team that helps families during this difficult decision. The goals of Palliative care are to

- Ease your child's pain and other symptoms of illness.
- Provide emotional and social support that respects your family's cultural values.
- Help your child's health care providers work together and communicate with one another to support your goals.
- Start open discussions with you, your child, and your health care team about options for care.

Next Steps for Continuing Pregnancies



How Will This Affect My Delivery Plan?

As the expected time of your baby's birth comes closer, you are preparing for all the normal changes related to having a baby as well as the reality of your baby's heart condition. After you have made decisions about how to move forward, you will wonder about how this will impact your pregnancy and birth plan.

Pregnancy and Birth Questions

How can my baby continue to grow and thrive with a heart problem?

During pregnancy the placenta does the work that the heart and lungs may have difficulty doing after birth due to your baby's heart issue. This is why most babies continue to grow and develop normally during pregnancy.

Is a baby with a heart problem more likely to be stillborn?

Mostly, babies with heart problems are not more likely to be stillborn than babies without a heart problem. If you have questions or concerns about this issue, please discuss this with your MFM specialist and/or fetal cardiologist. If your doctors are worried that this is a risk, they will share this with you and make plans for the baby to be closely monitored.

Can babies with heart problems be delivered vaginally?

Most babies with heart conditions tolerate a vaginal delivery very well. In fact, there are benefits to both mom and baby in having a vaginal delivery. However, in some cases a baby may not be expected to tolerate labor well or might be expected to need a surgical procedure shortly after delivery. In these cases, a caesarean section is typically planned.

Will I need an early induction of labor?

Having a baby with a heart condition doesn't usually require an early delivery. If possible, we prefer babies with CHD to be born as close to their due date as possible. Other obstetrical concerns may lead to early induction of labor. If there is any reason to consider early delivery, induction of labor will be discussed with you and your fetal cardiologist by your MFM specialist.

How will decisions be made?

Plans for the care of you and your baby are made with your entire team during a multi-disciplinary meeting (MDM). Your fetal cardiologist, your MFM specialist, a neonatologist, your obstetrician, and other healthcare professionals will all be involved in the discussion. You will be an integral part of this meeting. Your opinions and preferences are important and will be taken into account as we build your care-plan together

My Hospital Admission

When your baby receives a CHD diagnosis..

Your obstetrician will make sure that your care and delivery method are appropriate for both you and your baby's condition. They will work with the pediatric cardiologist to discuss what care the baby might need during and after delivery. Some infants do not need immediate specialized care after birth, and the delivery plan remains unchanged.

If your baby does need specialized care in the immediate period after birth, your delivery plan may include moving closer to a hospital prior to delivery. Your care team will advise you on when you need to relocate. Most larger, specialized hospitals can help parents find local housing to stay in prior to and after delivery. A social worker may be assigned to your case to help you.

What if I need help medical help before a planned delivery?

Please call your obstetrician and proceed to your nearest local hospital if:

- You feel you are in labor
- You have bright red bleeding
- You feel you are in an emergency situation
- You feel like the baby is not moving as much
- You feel the birth of your baby is about to happen
- You feel like your 'water' has broken or you are leaking fluid

How can I prepare for my hospital stay?

Wherever you plan to deliver, it is helpful to tour the hospital and labor delivery unit so this is familiar to you when you arrive

If you are relocating far from your home for delivery

- you will need local housing before and after delivery
- If you have other children, pets, elderly family members that need care, you will need to consider how their care will continue while you are away.

Prepare yourself for what the delivery room environment might be:

- There may be a lot of people in the delivery room
- You may or may not be able to hold your baby
- Your baby may need special care

Planning for delivery is usually an exciting and emotional time. But when your child has CHD, delivery planning may feel out of your control. This can be frightening or frustrating or both.

The best way to deal with uncertainty and mixed emotions about delivery is to understand what will happen and why. Getting more information and clarity about the delivery plan will help you and your partner feel empowered and more in control of the process.

What should I bring to the hospital?

For labor and delivery:

- Keep a copy of your fetal echo report or summary of your visit in your delivery bag, in case there is any confusion about your baby's diagnosis when you first arrive at the hospital
- Money for parking
- Phone charger
- Washable robe and slippers
- Toiletries such as a shower cap, toothpaste, toothbrush, mouthwash
- Labor coaching supplies
- Magazines, books, cards, music via battery operated device
- **For maternal/child care unit:**
- Supporting bra, breast pads, underwear
- Toiletries such as toothpaste, toothbrush, shampoo, comb, hairbrush, deodorant
- Comfortable clothes for when you are discharged

Who will be present at my delivery?

There will be several staff members present at your delivery: a team for you and a team for your baby.

Mom's team for a vaginal delivery consists of your partner/support person, your delivery obstetrician, a labor and delivery nurse practitioner, and the labor and delivery Nurses. There may also be medical trainees. If having a caesarean section, the team will additionally include members of the operating room (OR) team: an anesthesiologist, a scrub nurse, and a circulating Nurse.

In both cases, staff from the neonatal intensive care unit (NICU) will attend the delivery to take care of your baby after birth. The NICU team may consist of a transport nurse, one or two resuscitation nurses, and may possibly include a neonatal nurse practitioner, neonatal fellow, and neonatology attending physician.

A conceptual image showing four hands of different skin tones reaching towards the center to form a circle. The hands are positioned at the top, bottom, left, and right, with their fingers pointing inward. The entire image is overlaid with a semi-transparent green filter. The text 'Asking for Help' is centered over the hands in a white, sans-serif font.

Asking for Help

How Can I Get the Support I Need?

For many, the journey of prenatal diagnosis and CHD is like a roller coaster. There will be ups and downs, triumphs and setbacks. And you, of course, are along for the ride. Please refer to the “Resources” section of this booklet to learn more about online sources of support.

We encourage you to build a support team and create a mental health care plan in advance. The following tips might help.

Addressing Emotions

Give Yourself Permission to Cry or to Feel Overwhelmed

You may be concerned that if you let your feelings flow, you’ll never be able to pull yourself back together. You will. Allow yourself to feel the release of emotion. Tears can be therapeutic.

Keep a Journal

Expressing your feelings on paper can help. A journal may also strengthen your hope and patience by reminding you of how far you and your baby have come.

Accept the Support of Others

Let others know exactly what is most helpful (or unhelpful) to you. Be specific. People usually mean well, but don’t always know how to best support you.

Consider making a calendar to show when meals or childcare are needed, and to indicate when you are or aren’t open to visitors. Use chore lists that people could choose from.

Celebrate the Successes

When you or your baby make progress, let yourself feel the joy!

Peer Support

Sometimes, connecting with others who have walked a similar path can help.

Refer to the resource section of this booklet to learn more about how to connect with other parents.

Connect with Staff Who Help You to Feel Comfortable

- These staff members are often willing to listen supportively
- They can help to alleviate some concerns or pressing questions

Couple/Caregiver Interaction

You and your partner may react and process differently. Tell your partner what you need or would find most helpful. Ask for support from your healthcare team if you are having struggles with your relationship. They can help to guide you in accessing services or finding local community supports.

Finding Balance

- Establish a routine. Try to balance work, home, and medical care.
- Make time for yourself, your partner, your children and other significant others. Give them (and yourself) dedicated time.
- Take care of yourself. Take time for you each day. Give yourself a treat.
- Some find it helpful to reflect and lean on a personal spiritual perspective. Some people find comfort in speaking with a spiritual leader.

Social Workers

Social Workers are part of your healthcare team, and their role is to provide assistance with building a plan to address family needs and coping. Supports can include:

- Assistance with temporary housing if the hospital is far from your home
- Funding supports and financial counseling
- Coordination of time off work
- Referrals to community programs
- Assistance if you are experiencing mental health issues related to stress, grief or loss

You will meet one (or more) Social Worker(s) during your journey. Generally, a Social Worker will join your care team around the time of the multidisciplinary meeting (MDM) at about 32+ weeks gestation. They will give you information about the NICU and different resources that might be helpful to you. They will also offer you a tour of the NICU.

Social Workers may also be able to help address other concerns you might have like:

- I don't have a dependable partner
- I have a mental health condition
- I'm homeless
- I have issues with addiction
- I live outside of town
- I lost my job

If you need help right away, or you are unsure of which community/ counseling program would best meet your family's needs, you can speak with a Social Worker to best assess your situation. Speak to your Obstetrics care team, and/or your fetal cardiology team if you would like to speak with a social worker

A photograph of a man and a woman sitting at a desk in a home office. The woman, on the left, has curly hair and is wearing a floral top. She is looking at a laptop screen. The man, on the right, is wearing a striped sweater and is also looking at the laptop. The desk is cluttered with various items: a calculator, a mobile phone, several sheets of paper, and a small blue cup. The background shows a window with a grid pattern, suggesting a bright, airy environment. The overall tone of the image is soft and focused.

Online Resources

Gathering Information about Hospitals, Outcomes

[The Guided Questions Tool](#)

From the Conquering CHD website. Is a list of questions you may want to ask your Pediatric Cardiologist if CHD is diagnosed.

<https://www.conqueringchd.org/wp-content/uploads/2020/04/Conquering-CHD-Guided-Questions.pdf>

[California Heart Connection](#)

Has many useful handouts and links to information. Includes list of questions for the surgeon, resource guide, Forms for school, what to ask the insurance company. (Not California-specific)

<http://caheartconnection.homestead.com/Handoutsandforms.html>

[CHD Hospital Navigator](#)

From the Conquering CHD website, created specifically for parents. Is a list of specialized programs a hospital offers, volumes of surgeries broken down by complexity, as well as if the survival for the surgeries there are at expected levels. It also includes guidance about how to interpret the information provided. Not all hospitals have contributed their information to this site.

<https://www.conqueringchd.org/learn/hospital-navigator/>

[Society of Thoracic Surgeons Public Reporting](#)

Lists the outcomes of pediatric cardiac surgeries as they are reported by participating hospitals. Not all hospitals report their pediatric cardiac surgery outcomes, but you may still find information about a hospital on this site that is useful to you.

<https://publicreporting.sts.org/chsd>

US News and World Report Annual List of Best Children’s Hospitals for Cardiology and Heart Surgery

This ranking system attempts to rate measures typically associated with high quality care and can help inform you. These rankings do tend to vary significantly year to year without obvious changes in the programs themselves. Often this is due to a change in how they determine the rankings, rather than an actual change at the hospital.

<https://health.usnews.com/best-hospitals/pediatric-rankings/cardiology-and-heart-surgery>

National Pediatric Cardiology Quality Improvement Collaborative

This is a large national group of parents and health care professionals focused on improving care for children with CHD that has one (single) ventricle. They have many education resources for families, some are linked below.

<https://www.npcqic.org/tools-resources>

Learning about your child's heart diagnosis

[American Heart Association](#)

Descriptions of and diagrams for many forms of CHD. Also has lists of FAQs, lists of resources for parents, downloadable information pdfs.

<https://www.heart.org/en/health-topics/congenital-heart-defects/about-congenital-heart-defects>

[Heartpedia](#)

A free application that shows anatomically accurate images of 12 types congenital heart defects and repairs of those defects. Once downloaded onto your device, you can view the images for normal hearts, the defect (for comparison) and views of the surgical repair. Also includes video animation with audio description of each defect and repair (English), and read a detailed description of the defect.

<https://www.cincinnatichildrens.org/patients/child/encyclopedia/heartpedia>

For [iPhone, iPad](#): <https://apps.apple.com/us/app/heartpedia/id885512669>

[and Android](#) <https://play.google.com/store/apps/details?id=com.cardinal.childrensheartencyclopedia>

[Cove Point Foundation](#)

Information and diagrams about CHD, tests and surgeries

<http://pted.org/>

[The Children's Heart Foundation](#)

The primary focus of this group is to fund congenital heart disease research. Publishes the It's My Heart book for parents, which parents can order (free of charge), takes 1-2 weeks. Book has information about these and other CHDs, including treatment options. Website has very brief description, simple diagrams about common types of CHD.

<https://www.childrensheartfoundation.org/>

General information about CHD, logistics, emotional impact

CHD Care Compass

This website was co-written by parents and medical health professionals from across the US. Addresses the emotional impact of a new diagnosis, and covers all steps of the CHD care journey. Has parent videos and logistical information.

[Mended Little Hearts Guide](#)

Information booklet for parents that includes a wide range of topics, from discussions on the emotional impacts of CHD to practical information on delivery planning, nutrition, etc. (88 pages, English)

<https://lsc-pagepro.mydigitalpublication.com/publication/?i=546842>

[Mended Little Hearts Guide Lite](#)

Shorter version of Mended Little Hearts Guide (20 pages, English)

<https://mendedhearts.org/wp-content/uploads/2017/03/MLHGuide-Lite.pdf>

[Sisters by Heart](#)

SBH has many resources for parents with newly diagnosed hypoplastic left heart or single ventricle, including this page of guides

<https://www.sistersbyheart.org/guides-toolkits-nd>

[An Open Letter to a New Heart Mom](#)

https://www.aap.org/en-us/Documents/CHPCH_letter_to_a_new_CHD_mom.pdf

Programs that offer mental health care/childcare packages/financial support

Bright Heart Foundation (For Tennessee):

- Provides developmental support equipment
- Provides mental health care to those living with CHD, family members that care for those with CHD, and CHD healthcare providers.

<https://www.brightheartfoundation.org/>

Hopeful Hearts

Helps families with children with CHD by providing financial support.

<https://www.hopeful-hearts.org/whatwedo.html>

Sisters by Heart

SBH is a group of parents who have a child with Hypoplastic Left Heart Syndrome. They send care packages to parents of children with this diagnosis at the beginning of their journey.

<https://www.sistersbyheart.org/our-care-packages>

Ollie Hinkle Heart Foundation

OHHF provides free and reputable mental health support to heart family members in the St. Louis, Kansas City, and Chicago regions

<https://www.theohhf.org/heart-families/mental-health-services/>

Parent stories

Little Hearts

Website features family stories, listed by child's cardiac diagnosis.

<https://www.littlehearts.org/>

World Of Broken Hearts

Website that showcases photographs and stories about families and children affected by CHD

<https://www.worldofbrokenhearts.org/>

Children's Heart Foundation

<https://www.childrensheartfoundation.org/blogs/blogs-stories.html>

Tiny Tickers (UK based)

Features videos of families talking about their experiences as well as parent stories

<https://www.tinytickers.org/support-info/family-experience-videos/>

Connect with other parents

Conquering CHD for Teens and Adults

- Private group for teens and adults with CHD

<https://www.facebook.com/groups/conqueringchdteensadults/>

- Connect with members/parents from a [local chapter](#) (scroll to lower part of page). See if there is a chapter in your state, and reach out to the contact provided.

<https://www.conqueringchd.org/involvement/get-connected-connect-with-others/>

Kids With Heart

<https://kidswithheart.org/>

- Register for [free membership](#)

<https://kidswithheart.org/page/membership>

- If you would like to be paired with a parent mentor, (click on “join now”) and select services, or call 1-800-538-5390 and they will talk with you to learn about you in order to make a match with a parent.

[Facebook group](#) <https://www.facebook.com/groups/124571567596824>

[Facebook page](#) <https://www.facebook.com/kidswithheartnachd1985>

Little Hearts

- Hosts a private Facebook group for parents, newsletter.

<https://www.littlehearts.org/>

- If you would like to be paired with a parent mentor: sign up for a free [membership](#), options at the bottom of the page prompt you to request a parent match, and/or to be added to their parent Facebook group.

<https://www.littlehearts.org/become-a-member>

- Website features family stories, listed by child’s cardiac diagnosis.

Mended Little Hearts can match you with parent mentors through your [local chapter](#)

- If you would like to request a parent match/mentor, begin by reaching out to a local chapter contact.
- This website includes information for both **Mended Hearts**, which provides support for adult heart disease, and **Mended Little Hearts** (support for CHD).
- After you click on your state, for Mended Hearts Chapter contacts are listed first, and below that the Mended Little Hearts Chapter contacts are listed.

<https://mendedhearts.org/connect/get-help/find-your-chapter/>

[Linked by Heart](#)

- For families with child affected by HLHS/single ventricle.
- Has regional support (parent contacts; Sisters by Heart representatives) and Facebook groups that can be found on this page.

<https://www.sistersbyheart.org/linked-by-heart>

[Family Voices of Tennessee](#)

<https://www.familyvoicestn.org/get-connected/>

Grief and Bereavement Support

Conquering CHD

- [Facebook page for bereaved parents](#)

<https://www.facebook.com/groups/894948250657241/>

- List of helpful [resources](#) for those affected by grief, loss, or bereavement related to CHD

<https://www.conqueringchd.org/learn/bereaved-families/>

[A Heartbreaking Choice](#)

Support for those who have terminated a desired pregnancy

<http://www.aheartbreakingchoice.com/>

En Español

[Estamos Conquistando CHD!](#)

Grupo privado de Facebook para padres, alojado por Conquering CHD

<https://www.facebook.com/groups/ConquistandoCHD>

[Guía de pequeños corazones reparados Lite, versión en español](#)

Versión más corta de la Guía Mended Little Hearts (20 páginas)

<https://mendedhearts.org/wp-content/uploads/2017/03/MLHGuide-Lite-Spanish.pdf>

[Hermanas de corazón](#)

Información para familias con un niño recién diagnosticado con el tipo de cardiopatía coronaria de un solo ventrículo

<https://static1.squarespace.com/static/5f1b4f611f2eee5a5d06154b/t/5f221d0fbeacf06c0d1e83cf/1596071199352/2014FrontSpanishweb.pdf>

[Conexión del corazón de California](#)

Ficha de información sobre variados temas relacionados con las enfermedades del corazón en español.

http://caheartconnection.homestead.com/files/resources_in_spanish_0507.doc

[Fundación Cove Point](#)

Recursos educativos para padres sobre diagnóstico, pruebas y cirugías en español

<http://pted.org/>

[Asociación Americana del Corazón](#)

Descripciones y diagramas de muchas formas de cardiopatía coronaria.

<https://www.heart.org/en/health-topics/congenital-heart-defects/defectos-cardiacos-congenitos-de-los-ninos>

Notes

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