

KNOWING BUT NOT KNOWING

*Finding out about
your baby's heart
problem before
your baby is born*



Pregnancy is usually a time of

excitement and anticipation
plans and preparation
hopes and dreams.

Now this precious time has been interrupted by

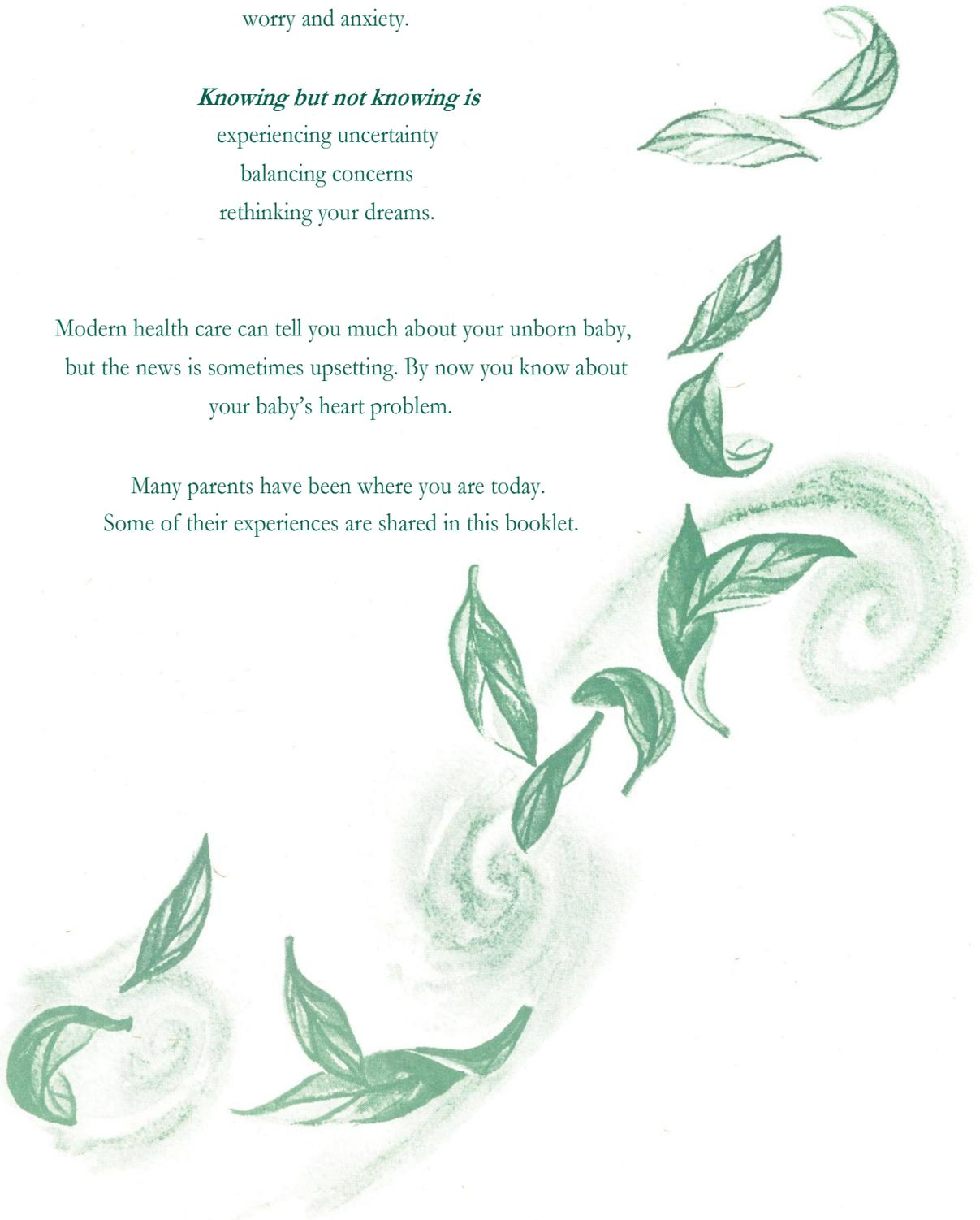
concern about your baby's heart
waiting for tests and information
worry and anxiety.

Knowing but not knowing is

experiencing uncertainty
balancing concerns
rethinking your dreams.

Modern health care can tell you much about your unborn baby,
but the news is sometimes upsetting. By now you know about
your baby's heart problem.

Many parents have been where you are today.
Some of their experiences are shared in this booklet.



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Finding Out About Your Baby's Heart Problem Before Your Baby is Born

Knowing But Not Knowing

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You Are Not Alone

You have recently found out that your baby has a heart problem. Whether you have been waiting days, weeks or months for the ultrasound of your baby's heart, you and your family may have already experienced a period of uncertainty and worry.

Now you are trying to make sense of it –

- the surprise
- the new words
- the flurry of questions
- the flood of feelings

Your baby's heart problem may be much less or much more serious than you expected. There may be difficult decisions to make about the care and treatment of your baby. In any case, you and your family are experiencing a life-changing event. Every family manages such events in their own way.

Through this booklet we hope to

- validate your feelings
- provide you with information
- talk about the decisions you need to make.



“Hitting a Brick Wall”

You will probably never forget this day. One father described finding out about his baby’s heart problem as “hitting a brick wall”. Most parents feel overwhelmed and try to make sense of what is happening. What does this information mean? With whom can we talk? Where do we go from here?

Answering Some Commonly Asked Questions

What is antenatal diagnosis?

Antenatal means “before delivery”. An antenatal diagnosis is what is detected about your baby’s health before birth.

What are congenital heart defects?

Congenital is the word used to describe health problems present at birth. The heart is completely formed by the 8th week of pregnancy. If the heart has not formed perfectly, the baby will be born with what is called a congenital heart defect, CHD for short. 5 to 8 out of every one thousand babies born has some type of heart defect (i.e., 0.5-0.8%). This ranges from a tiny hole in the heart that will never require treatment, to a life-threatening heart defect.

What causes congenital heart defects?

No one knows what causes most heart defects. You may hear the term “multifactorial causation”, meaning that no one thing causes the defect. This means that when certain genetic and environmental factors occur at the same time, a heart defect may result. It is important to know that there is nothing you did or could have done differently to prevent the heart defect from developing. If you have a family history of congenital heart disease, your chance of having a baby with CHD increases from less than 1% to at least 3%. Because heart defects happen only when a number of different factors come together by chance, science cannot predict the occurrence of congenital heart defects.

What is a fetal echocardiogram?

Fetal refers to the fetus or developing baby. An echocardiogram uses sound waves to examine the heart. It is possible to “see” the parts of the heart at about 18 weeks of pregnancy. Pictures of the baby’s heart taken by an ultrasound machine are closely examined by a specialist. These heart pictures are called the fetal echocardiogram.

How can you be sure that the fetal echocardiogram is correct?

Specialists in children's heart disease and high risk pregnancy have been examining fetal hearts since the 1980's. Their experience allows them to identify abnormalities in even very small hearts by eighteen weeks of pregnancy. Even with all of this experience, it can be hard to tell just how much the heart is affected until after the baby's birth.

Antenatal information can give parents and health care professionals valuable direction for making decisions about the pregnancy, the delivery, and care of the baby after birth.

Who can provide information about the baby's heart problem?

A pediatric cardiologist and a pediatric cardiac nurse clinician can help you find answers to your questions. Your nurse clinician is your navigator and will be available to support you and your family. The nurse clinician's role is to help you interpret the information presented to you, connect you with resources as needed, and help you to create a plan of care that meets the individual needs of you and your family.

Who can answer my questions about my pregnancy?

Your family physician and/or obstetrician will still be part of your care team. You and your family may also have the support of a perinatologist - a doctor who specializes in high risk pregnancy.

Who is on the health care team?

From now on you and a number of different health care professionals are the team collaborating and planning care for you and your baby. You will have thoughts, feelings, and information to share with us. We will have information and resources you need. In addition to the physicians and cardiac nurse clinician mentioned above, other professionals are available to join the team (e.g., social worker, chaplain, child life specialist). The cardiac nurse clinician can give you further information about the services each team member provides.

The number of people involved in the care of you and your baby can feel overwhelming. Please use the Directory on page 23 to record the names and numbers of those "on your team".

Will more tests be done and why?

Sometimes the congenital heart defect is associated with other health problems. In some babies the cause of their health problems can be explained by an abnormality in a gene or chromosome (the structure that holds our genes). For example, certain heart defects are often found in babies with Down Syndrome. In addition, the

presence of problems in more than one body system (e.g. a heart defect with a cleft palate) increases the chance that an underlying genetic defect is responsible for the baby's abnormalities. Because of this you may be referred to an expert in medical genetics.

You will receive more information about genetic testing via blood tests and/or amniocentesis from the geneticist as well as from your perinatologist if further tests are recommended.

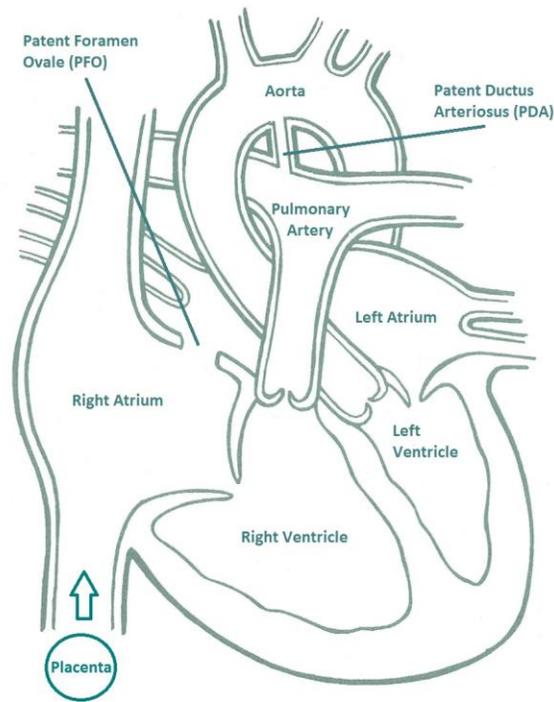
Follow-up fetal echocardiograms may give you more information about the heart such as growth of different parts of the heart. This will help you and your health care team make plans for managing your pregnancy and delivery and guide how best to care for your baby after birth.

Will the defect in the heart create other problems as the baby develops?

Even though parts of the baby's heart may not be forming normally, the blood flow through the fetal heart and mother's placenta is generally adequate to support the baby's growth and development. In most cases the baby is very safe inside the womb. If there are additional concerns about your baby's well-being during pregnancy, the cardiologist and nurse clinician will discuss this with you.



Heart structure before birth



What happens when the baby's heart must take over after birth?

The way blood flows through the heart changes in the first few days after birth. The lungs begin to do the work which the placenta has been doing. During this time the baby may start to show the effects of the heart defect.

Heart structure after birth

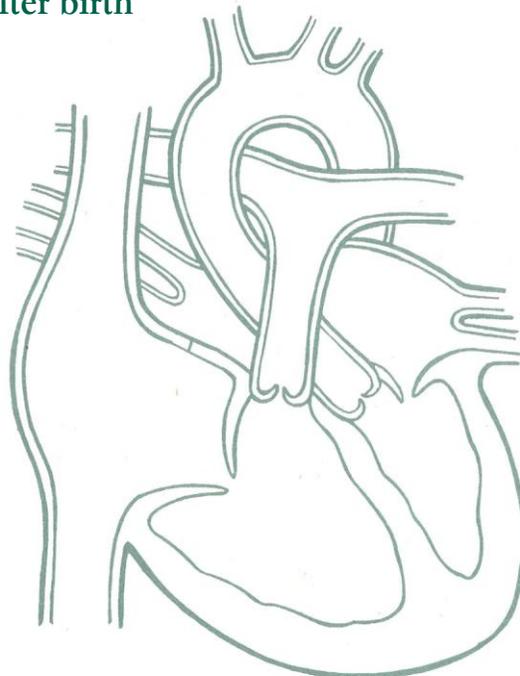


Diagram of our baby's heart problem



Additional information about our baby's heart problem



Choices and Decisions

Babies with mild or moderate problems

Most congenital heart defects can be treated. Some babies do well despite a mild heart defect and only require routine check-ups with the pediatric cardiologist. Other babies need medications to offset the effects of the congenital heart defect. Some babies will need surgery to treat or correct their heart problem.

Children with mild or moderate heart problems generally enjoy a normal life, although medical and surgical treatment may be necessary. Regular follow up with a pediatric cardiologist throughout childhood will help ensure that your child remains healthy and that any potential problems are treated as soon as they arise.

Since your baby's heart problem has been diagnosed antenatally, decision making may also include deciding where is the best place to deliver your baby.

At or near a specialty hospital

Your perinatologist and pediatric cardiologist will help you decide the best place for your delivery. Discuss with them the benefits of staying close to home in your community hospital or being near specialty pediatric care. Hospitals that specialize in the care of babies and children with congenital heart problems are the best choice if your baby will need immediate monitoring and treatment.

At or near your community hospital

When it seems that your baby will not need immediate medical care, we recommend that you deliver your baby in your home community. This allows you to enjoy family, friends and familiar surroundings. Your pediatric cardiologist will let you know when to bring your baby for specialized cardiac assessment.

(Record information on pg. 22)



Babies with severe heart problems

For those of you whose baby has been diagnosed with a severe heart problem, you are in the middle of a very challenging experience. The life-threatening nature of your baby's heart problem makes your choices and decisions extremely difficult. It is important to know that there are no right or wrong decisions and your health care team is here to support you regardless of the path you choose.

Some thoughts on making hard decisions are as follows:

- Find out as much as possible. Make a list of your questions and try to take a few notes during your appointments with professionals so that you can talk things over at a later time.
- Information is very important. Some questions to consider might be:
What are the treatment options for your baby? What are the risks involved? What are the best and worst outcomes? How much time do you have to make the decision? What will living with a complex heart problem be like for your child and family? What are the risks in other pregnancies?
- Ask the people who are important to you to be with you when you are given information.
- Keep a journal with your questions and concerns as they arise so you can share them with your care team.

Think about seeing a counselor, social worker, chaplain or spiritual/religious leader from within your community to talk about your challenging choices and decisions. The pediatric cardiologist and cardiac nurse clinician involved in your diagnosis of congenital heart disease are available to discuss your questions and concerns about your baby's heart problem both during your visits to the hospital and by phone or email between your appointments.



Considering surgery for you baby

Surgery to treat severe heart problems presents a risk to the baby's life but the chance of survival is usually high, even for babies with very complex heart problems. The child may need several surgeries in the first few years and subsequent surgeries or procedures may be required later in the child's life.

After considering the risks and benefits of complex surgery, parents, in consultation with the pediatric cardiologist and pediatric cardiac surgery team, may choose surgery knowing that despite the risks there is a good chance that their baby will survive and do well.

Again, be sure that you get all the information. What are the surgical options? What are the risks and benefits? What are the best and worst outcomes? When would surgery be? How many surgeries? What will living with a complex heart problem be like for your child and family.

Considering heart transplantation for your baby

Heart transplantation is a treatment option for some babies, depending on the severity of the heart defect as well as the presence or absence of other health conditions or underlying genetic problems. Transplantation is not usually the first option considered as donor heart availability is unpredictable and very limited.

The risks involved with heart transplantation include those associated with waiting for a donor heart, as well as surgical risk. Heart transplantation also involves ongoing medical follow-up and lifelong medications to control rejection of the donor heart. Questions to ask may include: When and how could my baby become eligible for a donor heart? Are there situations where heart transplantation is not an option?

The pediatric cardiologist and cardiac nurse clinician will give you further information about transplant services and available resources.

Considering palliative care for you baby

After considering the complex nature of your baby's heart condition, you may choose to continue your pregnancy and provide palliative or compassionate care for your baby after birth. This type of care may include using medications and interventions to keep your baby comfortable. Rather than intervening to prolong your baby's life, the medical team will focus on supporting your family to spend the limited time you have together in the way that feels right for you. Things to ask about may include: What would our baby's short life be like? Sleeping, eating, comfort? What would our baby's death be like? Who would be there to help us? Would our baby be at home? In the hospital? In a hospice? Who would help us after our baby's death? Some babies live for hours, some for days. A few live for months. Quality of life for the baby and family is the goal rather than surgical or medical treatment.

Considering ending your pregnancy

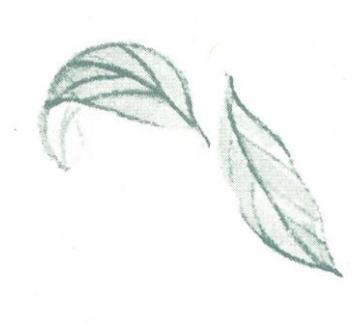
Depending on your stage of pregnancy, one of the choices that may be presented to you is that of ending your pregnancy. For some of you this may not be a consideration because of your personal beliefs. For those considering the option to end your pregnancy, it may be the most difficult choice you ever contemplate.

Your family physician, obstetrician, and perinatologist are helpful sources of information about the option of ending your pregnancy. They can direct you to other people and services who can support you through your decision making.

This is a lot of information!?

There may be times when you feel bombarded with too much information. One mother felt like saying “Leave me alone. I don’t want any more information.” It is okay to let others know that you need time to absorb the information you have already received.

Keep in mind that seeking information is only one way to cope with your uncertainty. If it is your only way of handling difficult situations, you may feel that you never have enough information. This may be a sign that you need to consider some other ways of coping such as: dealing with your feelings, readjusting your expectations and maintaining a positive approach.



Tackling the “Brick Wall”

The shock and intense feelings surrounding the antenatal diagnosis can be overwhelming at first. As you feel the feelings and talk about them with others, you will begin to find ways of coping with this unexpected life event. You will be amazed at your strength and the resources available to help you tackle the “brick wall”.

Feel the feelings

Pregnancy is a time of intense emotion. Feelings of celebration, excitement, anticipation, joy and relief are felt together with feelings of uncertainty, reflection and wonder.

As parents await the birth of their baby who they know has a heart problem, they struggle to balance their feelings of excitement and celebration with their worry and disappointment. All parents struggle to come to terms with the thought that the baby they have dreamed about will be different from the healthy baby they expected. You are not alone in what you are feeling. Parents have repeatedly shared their stories with us.

Fear

When parents find out that their baby has a heart problem, many are afraid that their baby will die. They describe feeling “*terrified*”, “*frightened*”, and “*scared*”.

Many parents say they feel physically sick. Some feel like running away or escaping.

Shock

No one is ever truly prepared for bad news - even when they are expecting it. Most parents are shocked. Many give reasons why this cannot be happening to them.

Parents talk about how healthy or “how good” they have been during the pregnancy. They have been “*eating right*”, “*living carefully*”, not drinking, not smoking, and/or not taking drugs – “*I didn’t even take an Aspirin*”.

Other parents are shocked because they already have had healthy children, and have been anticipating another healthy baby. Some parents are surprised that their baby has a heart problem because “*there is no family history of heart problems*”.

Searching

At first, parents have difficulty believing that their baby has a heart problem. As the news starts to sink in, one of their first questions is “*What caused it?*” or “*why is this happening to me?*”

Parents sometimes wonder if they are at fault. One mother believed that her smoking and drinking over Christmas was the cause of her baby's heart problem. These suspicions are often untrue, and the feelings of blame, self-doubt and guilt are not easy to discuss.

One father said: *"I felt inadequate, you know, that maybe it was myself... it's just a feeling of inadequacy that you can't perform properly and make a normal baby... or you have done something wrong."*

Worry

Parents describe feeling *"out of control"*, *"really upset"*, *"unstable"*, *"all worked up"*, *"very depressed"*. Parents worry about their baby's heart problem and about the effect this worrying could have on the baby and on their pregnancy.

"I started crying... cause you don't know what it means." Almost every parent cries. They may cry at different times and places and worry about upsetting others with their crying.

Anger

"I was so mad." Some parents respond with anger. They may be angry at God. Some are angry with health care professionals whom they feel have influence over their child's health.

Some are angry that an ultrasound done earlier in their pregnancy did not detect the heart defect.

Confusion

Parents often describe their feelings of confusion: *"It seemed like someone took the world and turned it upside down all of a sudden"* or *"the apple cart is upset and you can't handle it"* or feeling *"thrown out of wback"*, *"lost and helpless"*, *"unraveled"*, *"upside down"*.

These feelings of confusion and worry can make it hard to get on with daily life. You may wonder what to do with your feelings, or even ask yourself if your feelings are normal.

Relief

Many parents also express feelings of relief. They are relieved that they have time during the rest of the pregnancy to gather information and make decisions about the care and treatment of their baby. They may also be relieved that they have time to work through some of their intense emotions. Some parents even manage to regain a sense of celebration and anticipation of their baby's birth.

Talk about your feelings

As parents begin to adjust to the news of their baby's heart defect and talk about their feelings, their initial sadness, guilt, fear, helplessness, and depression become less intense. Many begin to feel more hopeful and regain a sense of excitement and anticipation about their expected baby.

As you talk about your feelings you will probably better understand your behaviours. Getting your feelings "out in the open" may decrease the tension you have been feeling and add to your sense of hope and anticipation.

You and your partner will experience different feelings at different times and cope with these feelings differently. Sharing your thoughts and feelings with your partner helps both of you to understand and respect each other for where you are at. Many are surprised at what they learn about each other during this unexpected experience.

Some parents find it hard to talk about their fears, even though they are thinking about them constantly; "... it's too scary to talk about it."

Acknowledging and expressing our feelings requires considerable effort. Creative expression through such things as journal writing, art, music, gardening, or other hobbies can also be helpful means of expressing your feelings. Maintaining a healthy lifestyle including physical activity, a nutritious diet and relaxation activities also helps relieve stress and tension.

Build on your strengths

The strengths within you and your family have undoubtedly helped you tackle past challenges and demands successfully.

Take some time to reflect on who you are and what has helped you and your family cope with difficult situations in the past. These are the strengths and resources that you can use and build on in the days and months to come. Such strengths could include:

- Your personal views – Awareness of your beliefs and how they guide your choices may help you understand why you do one thing and not another. Personal views that can aid you in your decision making might include values related to quality of life. Beliefs such as, "everything happens for a purpose" or "you will not be given more than you can handle in life", may also give you strength and courage.

- Faith or hope in something or someone beyond yourself often brings comfort.
- Prayer, meditation, and spiritual counsel can be helpful.
- Becoming more informed may give you a feeling of being more in control and help you make more informed decisions and choices.
- Thinking positive and hopeful thoughts gives strength to many people.

Inform your family and friends

Some people know just how to listen and comfort. Unfortunately, not all friends and family are supportive in times of need. You may hesitate to share your feelings immediately, but may also want the closeness that this sharing brings.

A number of things often happen as you begin to share your news with others. You may feel:

- Supported by your family and friends as they listen and offer comfort.
- Frustrated because your well-meaning friends and family members tell you not to worry. They do not seem to understand.
- Anxious about the questions people ask that you do not have answers for or have not even thought to ask.
- Alone as some of your family or friends seem to withdraw from you and your family.
- Sadness and grief. Your telling others may make your baby's heart problem feel more real to you and telling other family members may cause them to experience their own feelings of sadness and loss.
- A sense of relief that others now know your news.

It may be helpful to think about how each of your friends or family is likely to respond to what you tell them. You can always say things later, but you can never “untell” your story. Take your time. This is your experience and your choice.

Build your support team

Remember – you are not alone. Your friends, family members and work colleagues want to help. Some may not know how to help. Tell your support team specifically what is helpful and what is not. For example:

- “Just listening to me is helpful. It’s hard when people tell me not to worry.”
- “It’s OK to ask me how I’m doing.”
- “How about taking the kids this weekend so John and I can have some quiet time alone?”
- “I can’t seem to pull the meals and housework together these days - any help would be wonderful.”
- “Come with me to my next fetal echocardiogram.”
- “I need some time off to deal with all of this.”

There may be others, who have not immediately come to your mind, who could be valuable sources of support for you and your family. Consider the advantages of letting others know of your situation and needs. Local community organizations such as clubs, churches, and community centers can offer financial and other forms of assistance.

Health care professionals in your community such as public health nurses, your family physician, community social workers, and/or family counselors can assist you during this difficult time.

Look for support from those who have shared similar life experiences of grief, loss and uncertainty. Talk with them about making tough life decisions. Parent and family support networks may be a source of this kind of support. (Obtain contact numbers of support networks from the cardiac nurse clinician.)

Remember, you are in charge of building your support team. Keep asking yourself:

“What do I need to help me cope right now?”

“Who will be the best ones to support us?”

“Is this person stressing me or supporting me at this point?”

Re-adjust your expectation

“I was hoping that things would be perfect.” Until receiving news about your baby’s heart problem you, like most parents, were hoping for and anticipating a “perfect” baby. Now you are having to re-adjust your expectations.

Feelings of grief characterize this “letting-go” of your previously anticipated hopes and images of your baby. Re-thinking the rest of your pregnancy, imagining what your labour and delivery will be like, and anticipating your baby’s birth and future all involve a shift in your expectations.

Knowledge of your baby’s heart problem does not, however, prevent you from continuing to feel excited about your baby’s arrival and to continue to imagine what your baby will be like. What will she feel like in your arms? How much will he weigh? Will you have a boy or a girl? What name will we choose?

Some of you will not want to know the sex of your baby so that there is still this surprise of pregnancy left to anticipate. Some of you will know the sex of your baby and will enjoy calling your baby by name.

Maintain a positive approach

“We’re still having a baby.” Some parents feel that they have to remind themselves that they are still having a baby! Despite the “knowing but not knowing” aspect of antenatal diagnosis, many parents positively respond by focusing on the baby. They continue to celebrate the growing and developing baby and the baby’s movement reassures them. “Every day I go like this [touches belly], then ... kick, kick, kick, so I know he’s strong.”

Most parents emphasize the importance of thinking positively - “kicking those negatives”. They consider the positive aspects of finding out about their baby’s heart problem antenatally.

A less obvious yet powerful way of maintaining a positive attitude is evident in the way that many parents prepare themselves for the worst, while at the same time hoping for the best. “We prepared ourselves for the worst case scenario... we figured we’re ready for the worst and anything better is going to be good news.”



Looking Ahead

Some pregnancy-related questions

After you have had time to think about your baby's diagnosis of CHD and are looking ahead to your baby's birth you may be wondering about a few things.

Here are some commonly asked questions related to the remainder of your pregnancy.

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

During pregnancy, the placenta does the work that the baby's heart and lungs may have difficulty doing after birth because of the heart problem. This is why most babies with heart problems continue to grow and develop normally during pregnancy. Your baby will likely not be smaller or larger at birth because of the heart condition.

Can babies with heart problems be delivered vaginally?

The placenta supports the work of the baby's circulation until the umbilical cord is cut after the birth. Most babies with heart problems cope well with a vaginal delivery. There is no increased risk. In most cases it is not until after birth when the circulation patterns in the newborn heart change that you will start to notice the signs and symptoms of the heart problem.

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

Generally, babies with heart problems are no more likely to be stillborn than babies without heart problems. If you have questions or concerns about this it is important to discuss them with your perinatologist.

What about early induction of labour?

The heart problem does not make earlier delivery necessary. Other obstetrical concerns during pregnancy may lead to early labour induction. Your perinatologist will discuss any plans for induction with you and your pediatric cardiologist.

“He cried!”

Many parents express surprise and relief that their baby seems so healthy after delivery. They had visions of a “blue” and “sickly” baby without the energy to cry at birth.

Many of you will enjoy relaxed time with your baby after birth. Your baby’s colour and easy breathing will reassure you that he or she is managing life outside the womb. Tears, feelings of amazement and picture taking highlight this wondrous time of welcoming your baby into the world. You now know what it feels like to have your baby in your arms.

This is an important time to hold, talk to, and breastfeed your alert and interactive newborn. Your time with your baby can and should be the first priority as long as your baby is pink and breathing easily.

In some situations, however, it is soon evident that the baby is in distress; perhaps not as pink and/or breathing harder or faster than most babies. There is still time for you to hold the baby, to take some photographs and even put the baby to the breast. The health care professionals will be keeping a close eye on your baby during this time. As soon as your baby needs attention he or she will be transferred to an intensive care unit.

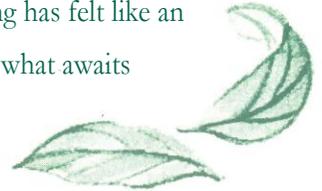
A pediatrician (a physician specializing in the care of children) examines your baby after birth. Your baby’s condition determines when the pediatric cardiologist will see your baby.

Most babies whose CHD has been diagnosed antenatally are seen by the pediatric cardiologist within one month of birth for confirmation of the antenatal diagnoses. An echocardiogram will be done and you are informed of the treatment plans. Babies with severe heart problems will require assessment by the pediatric cardiologist within the first hours of life.



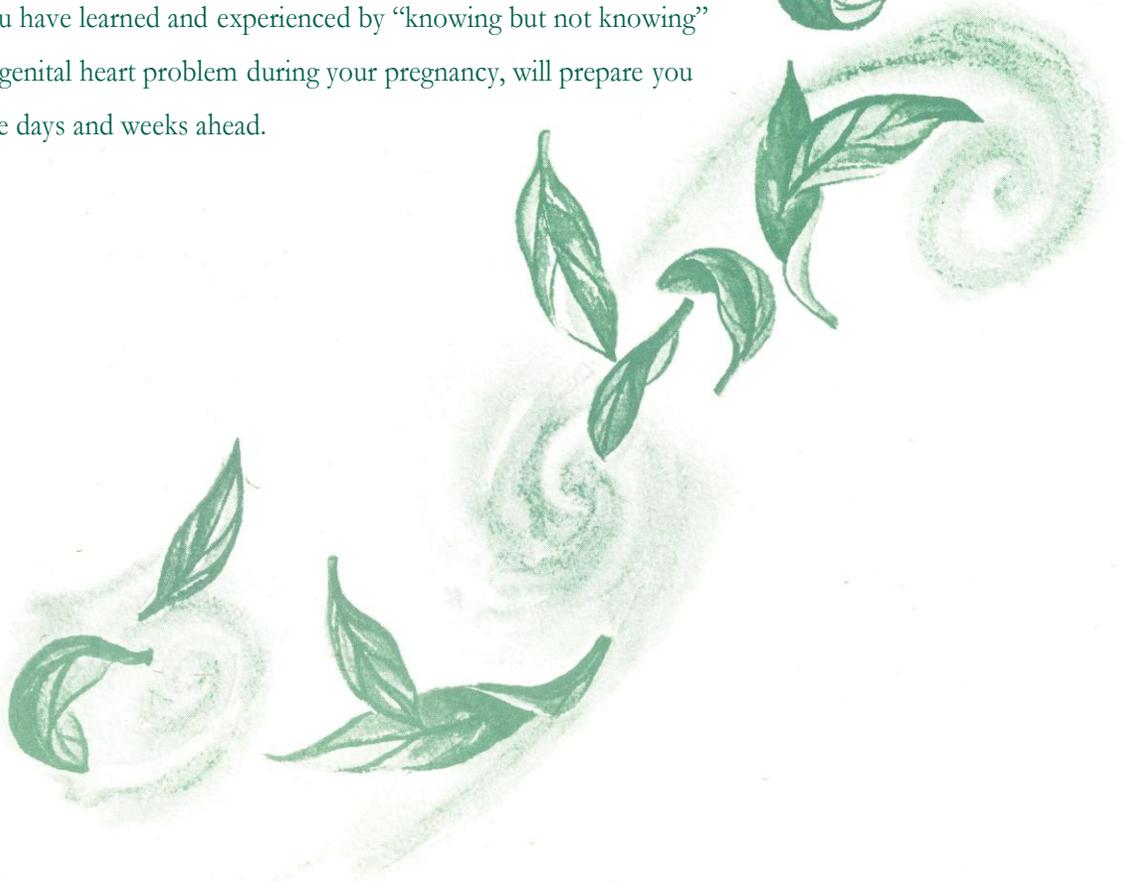


As the time of your baby's birth approaches, you are preparing yourself for all the normal things related to having a baby, as well as for the reality of your baby's heart problem. Soon you will know more about the impact of your baby's antenatally diagnosed heart problem. For some of you the waiting has felt like an "eternity" and the birth is not coming fast enough. Others wait patiently knowing that what awaits them will be joy and relief mixed with worry and then perhaps a new set of challenges.



You are not alone.

Many parents have gone through the experience of antenatal diagnosis and are available, along with the health care professionals, to support and help you on your way. We hope that what you have learned and experienced by "knowing but not knowing" about your baby's congenital heart problem during your pregnancy, will prepare you and your family for the days and weeks ahead.



So Where Are Things At?

My baby's heart condition is called:

Diagram of heart problem on page 6 of this booklet completed

Ongoing questions:

(Check them off as they are answered. Space is given to record the answers.)

Continuing your pregnancy:

- Names and numbers of health care professionals recorded in Directory pg. 23
- A repeat echocardiogram is recommended at _____ weeks gestation.
- Your next echocardiogram is booked for _____.

Planning for your baby's birth

- It is recommended that your baby can be safely delivered at your local hospital under the care of your family doctor and/or local obstetrician.

We recommend that your baby be seen by a pediatric cardiologist at _____ weeks of age.

- It is anticipated that your baby may need close observation and a detailed assessment by a pediatric cardiologist within a few hours after birth.

We recommend that your baby be born at _____ Hospital to best meet your baby's needs.

The cardiac nurse clinician can help you to prepare for this experience. As you get closer to the expected date of your baby's arrival, your nurse clinician will discuss with you the details of your baby's hospital care after birth. This is an especially important part of your preparation if your baby is expected to need heart surgery before leaving the hospital. Your nurse clinician will also:

- Arrange for you to tour the pediatric intensive care unit (PICU) and cardiac inpatient unit
- Arrange a meeting with a cardiac surgeon to discuss the plan for surgery

- Palliative or compassionate care is a possible care alternative for your baby. Should you consider pursuing this option, the cardiac nurse clinician can help you prepare for this experience and connect you with the palliative care team.

- Heart transplantation is a possible care alternative for your baby. Should you consider pursuing this option:

We recommend that your baby be born at _____ Hospital to best meet your baby's needs.

The cardiac nurse clinician and/or transplant coordinator can help you to prepare for this experience.

Directory

Pediatric Cardiologist

The pediatric cardiologist involved in your baby's antenatal diagnosis is _____

Cardiac Nurse Clinician

The nurse clinician available to work with your family is _____

Pediatric Cardiac Surgeon

The pediatric surgeons in our program are _____

Perinatologist

The perinatologist involved with you and your baby's care is _____

Other team members (Chaplain, social worker, child life specialist, aboriginal liaison, reproductive mental health, palliative care)

Others available to work with your family are: _____

Parent Support Network: Children's Heart Network - www.childrensheartnetwork.org

Internet Resources

- BC Children's Hospital - www.bcchildrens.ca
- Boston Children's Hospital - www.childrenshospital.org/conditions-and-treatments/conditions/congenital-heart-defects
- Children's Hospital of Philadelphia - www.chop.edu/centers-programs/cardiac-center
- Cincinnati Children's Hospital - www.cincinnatichildrens.org/patients/child/encyclopedia
- Johns Hopkins Hospital - www.pted.org
- The Royal Children's Hospital Melbourne www.rch.org.au/cardiology/heart_defects/
- Western Canadian Children's Heart Network - www.westernchildrensheartnetwork.ca

Notes



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