



# Antenatal Information

A guide for parents following an antenatal diagnosis

# ANTENATAL DIAGNOSIS

Being told your baby has a problem with its heart is both shocking and frightening for parents, as in many cases it may not be possible to make an accurate diagnosis until the twentieth week of pregnancy.

There are many different congenital heart defects (problems that the baby is born with).

Some are minor problems such as heart murmurs which may not need any treatment.

Others, although more serious, can be corrected with an operation.

The third group are extremely serious conditions. A series of surgical operations can be offered to allow a chance of life, but the child will never be cured of their condition. The child has to learn to live within lifestyle restrictions and, as a result, has an uncertain future.

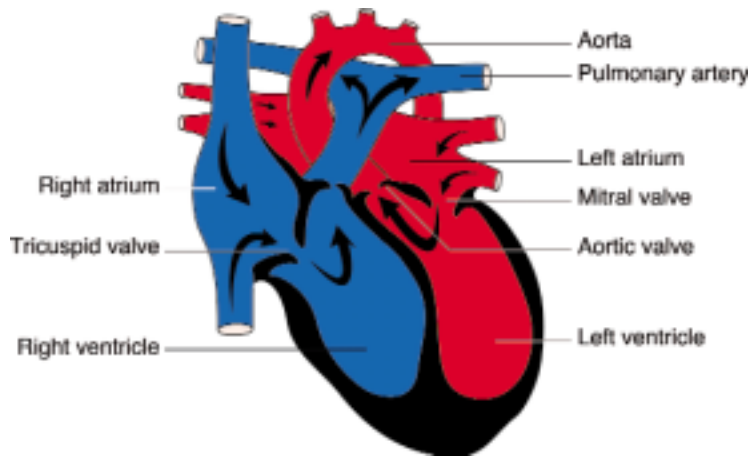
**In this information pack we aim to help parents understand these extremely serious abnormalities of the heart, what implications they will have for their baby and what treatment choices they have.**

# THE DIAGNOSIS

❖ I don't really understand what is wrong with my baby.

In order to understand what is wrong with your baby's heart, it is important to have an understanding of how a normal heart works and how the heart works whilst the baby is still within the womb.

## THE NORMAL HEART

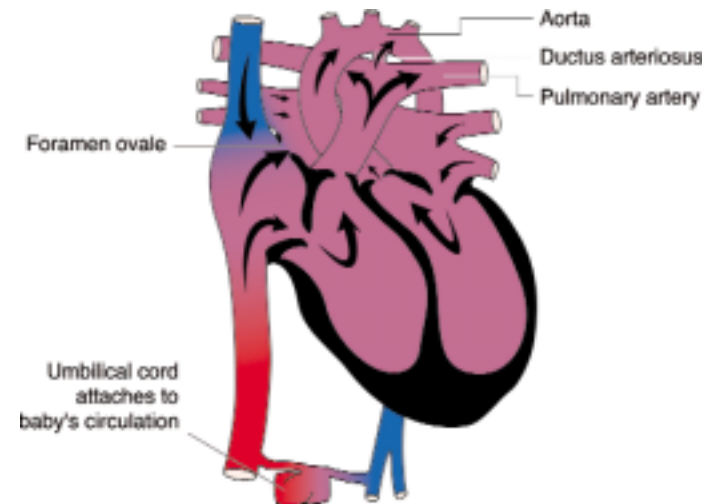


This is how the journey begins: blood returns from the body, via veins, to the right side of the heart into a collecting chamber called the right atrium. This blood has a bluish tinge (blue blood) because the body has extracted oxygen from it (deoxygenated blood).

The blood is then passed through a valve (Tricuspid) to a pumping chamber (Right Ventricle), which pumps the blood to the lungs via the lung arteries (Pulmonary Arteries).

The blood picks up oxygen as it passes through the lungs which turns the blood a red colour (oxygenated blood). This blood then returns to the left collecting chamber (Left Atrium) and it then passes through a valve (Mitral) to the left pumping chamber (Left Ventricle). The Left Ventricle then pumps blood to the body through a valve (Aortic) and to the body via the body artery (Aorta). The body uses the oxygen from the blood turning it blue again. And the journey starts again.

## THE CIRCULATION BEFORE BIRTH (FETAL CIRCULATION)



When the baby is still in the mother's womb it does not need to breathe for itself as the mother, via the umbilical cord, is supplying all the oxygen to the baby.

The circulation before birth is different from that after birth. It is designed so that the oxygen-filled blood from the umbilical cord goes to the most important part of the body, for example the brain. Very little blood needs to go to the lungs.

There is a hole between the top collecting chambers called the Foramen Ovale: oxygen filled blood passes from the right collecting chamber to the left collecting chamber through the hole and then on into the left pumping chamber from where it is then pumped around the body.

There is also a connection called the Ductus Arteriosus which joins the lung artery (Pulmonary) and the body artery (Aorta): blood passes from the right pumping chamber up the lung artery, some blood then passes to the lungs but most flows through the duct to the body artery and then around the body, again avoiding the lungs.

When the baby is born and starts to breathe for itself, the bypass systems are no longer needed. Gradually over the first few days or weeks after birth, the duct and the hole will close off and the baby's circulation will be as described on the page opposite.

## ❖ What exactly is wrong with my baby's heart?

A detailed account of each specific heart abnormality (with diagrams) will be discussed with you by the Fetal Cardiac Specialist. For more information look at the diagnosis section of the filofax where you will find diagrams and a simple written description of the heart problem. Take the information to future appointments with your medical team, they will use it as a tool to help you gain a greater understanding of the heart problem.

The written information can be a reference point when you go home. It can also be very helpful when trying to explain the heart problem to family and friends.

## ❖ Why has my baby got something wrong with its heart?

The baby's heart is being formed at around the fifth week of a pregnancy, just at the stage when you realise you are pregnant. In most cases it is impossible to give a specific reason for there being a heart defect. In the majority of cases the reason is not currently known. However...

There are a number of factors which are known to increase the risk of having a baby with heart problems such as:

- A history of previous children, either parent or other family members having had a congenital (born with) heart problem.
- There may be a fault in the baby's genetic make-up which has caused the heart defect. (See Genetics section).
- Diabetes in the mother, particularly if poorly controlled.
- Illegal drug abuse or serious alcoholism.
- Some medications such as those used for the treatment of epilepsy carry a small risk of causing heart problems, but are essential for the mother to keep her healthy and well.
- Other problems with the baby, for example, stomach or bowel.

## ❖ Did we cause the baby's problem?

Parents often worry that they are responsible in some way for the baby's heart condition, but it is highly unlikely that there is anything you have done or not done which would have caused the problem.

## ❖ What further tests will we need?

When any abnormality is found in a baby, it always raises the question whether it has been caused by a problem with the baby's chromosomes (genetic make-up). (See Genetic information). Some heart problems are caused by a fault in the baby's genetic make-up and may be part of a genetic syndrome such as Down's syndrome.

**However it is important to understand that most babies with heart problems will have an entirely normal genetic picture.**

### Tests Available

There are currently three diagnostic tests available which look at the baby's genetic make-up:

#### Amniocentesis

Taking a sample of fluid from around the baby.

#### Fetal Blood Sampling

Taking a sample of blood directly from the baby.

#### Chorionic Villus Sampling

Taking a sample of the placenta.

### Amniocentesis

- This is the most commonly used diagnostic genetic test as it has the lowest rate of miscarriage (0.5 - 1%).
- A fine needle is guided, by scan, through the abdominal wall into the uterus where a sample of fluid from around the baby is taken.
- The skin cells shed by the baby into the fluid are grown (cultured) and examined to give the chromosomes (genetic make-up) of the baby.
- An initial result will be available within 2 - 3 days which looks for the three major chromosome abnormalities, Down's syndrome, Edwards' syndrome and Patau's syndrome.
- The complete test results will take 2 - 3 weeks.

### Fetal Blood Sample

- This test has a slightly higher rate of miscarriage (1%) than amniocentesis.
- A fine needle is guided, by scan, through the abdominal wall into the uterus where a sample of blood is taken from the umbilical cord or from a small blood vessel in the baby's abdomen.
- This test has the advantage of the complete result being available in 5 - 7 days.

### Chorionic Villus Sampling

- This test is rarely used, but on occasions where there is very little fluid around the baby, it may be the preferred option.
- The miscarriage rate is 1 - 2%.
- A fine needle is guided, by scan, through the abdominal wall into the placenta where a small sample is removed.
- An initial result will be available within 2 - 3 days which looks for the three major chromosome abnormalities, Down's syndrome, Edwards' syndrome and Patau's syndrome.
- The complete test results will take 1 - 2 weeks.

All of these tests carry a risk of miscarriage and it is therefore extremely important that parents are encouraged to think through the implications of what they would do with the additional information.

Talk to your midwife or obstetrician to see what would be the most appropriate test, if any, for you.

### ❖ What is the advantage of having a test?

Every couple will need to think through the reason why they might choose to have a test. Some considerations are explored below.

Some parents feel that they need to know whether the heart problem in their baby is part of a genetic syndrome, such as Down's syndrome, as this additional information may help them choose the way forward.

There are certain serious genetic conditions which may mean that the baby will not survive pregnancy or live for long after birth and parents may be advised that the option for surgery would not be in the baby's best interest.

For some parents, knowing their baby has a genetic syndrome in addition to a major heart abnormality, may help them with the difficult decision of whether or not to continue with the pregnancy.

Other parents choose to have a genetic test in order to obtain as complete a picture of their baby's problems as possible, so that they can prepare themselves and their families during the remainder of the pregnancy.

### ❖ Who can help me understand the condition?

You may have been initially alerted that there is a problem with your baby's heart by a radiographer/sonographer carrying out a routine scan. Understandably they will not be able to give you a detailed diagnosis, but will refer you as quickly as possible to a Specialist Fetal or Paediatric Cardiologist.

You will probably be feeling overwhelmed by the amount of complex and upsetting information you are trying to take in. You will be given written information about your baby's heart condition to refer to and the contact numbers of Specialist Midwives in Fetal Medicine and Specialist Cardiac Liaison Nurses from the children's cardiac unit. The role of these specialists is explained below.

### **Specialist Paediatric Cardiologist**

This is a children's doctor who specialises in the care and treatment of babies and children with heart conditions, who will give you the diagnosis and discuss at length the implications for your baby.

### **Fetal Medicine Consultant**

This is a doctor who specialises in the care and treatment of pregnant women whose babies have some abnormality, who may also carry out a scan to check whether there are any additional problems in the baby and discuss with you whether you would like any further tests.

### **Obstetrician**

This is a doctor who specialises in pregnancy and the delivery of the baby. You may have an obstetrician close to your home who manages the day-to-day issues of pregnancy and an obstetrician who works as a fetal medicine expert at the regional specialist maternity unit.

### **Specialist Midwives in Fetal Medicine**

These specialist midwives are highly experienced in supporting parents through the many difficult decisions to be made following the diagnosis of an abnormality in their baby.

They will be able to spend time with you going over the diagnosis, and may discuss the pros and cons of further tests and the choices available to you. They will give you written information and contact numbers for other sources of support.

### **Specialist Cardiac Liaison Nurses**

These nurses are usually based in the children's hospital where the heart treatment will take place. They are highly experienced in supporting parents whose children are having treatment for heart conditions and are a valuable source of information and support for parents whose unborn child has been diagnosed with a heart abnormality.

They have first-hand experience of the emotional strain parents experience when their children are having major surgery, together with coping with the practical issues of everyday life.

They will be happy to talk to you about any of these issues, together with arranging a visit to the unit at some point prior to the birth if that is what you would like.

### **Further Sources of Support and Information**

**Little Hearts Matter (LHM)** is a national charity that offers unbiased information about the diagnosis, treatment and lifestyle of children diagnosed with a single ventricle heart disorder.

The charity offers support whenever a diagnosis has been made, linking parents with similar experiences and offering a national network of support via the telephone, website and group meetings. The support offered includes specific antenatal support, either on the phone or on the website message boards.

The charity also works to raise awareness of the needs of children, and their families, diagnosed with these complex disorders.

Contact Telephone Number: **0121 455 8982** or visit [www.lhm.org.uk](http://www.lhm.org.uk)

**Antenatal Results and Choices (ARC)** is a national charity which offers non-directive support and information, throughout the antenatal testing process, to parents seeking a greater understanding of the antenatal treatment options available to them.

ARC offers a telephone helpline, an email support group and a series of publications, for which you may incur a small charge.

Contact Telephone Number: **0207 631 0285** or visit [www.arc-uk.org](http://www.arc-uk.org)

**The internet** provides instant access to information for many parents who, understandably, are seeking additional knowledge about their baby's condition.

Many websites, such as those we have recommended, are excellent and well respected by professionals who promote them.

We would not dissuade parents from using the internet, but would point out that some sites are not always objective in the way they present their facts.

# THE CHOICES

Having received the diagnosis and the results of any subsequent tests, the specialist medical team will explain the treatment options available.

In the case of a single ventricle disorder where there is no opportunity of a cure, three treatment paths may be discussed.

- Surgical treatment at birth.
- Termination of the pregnancy.
- Comfort care.

Each treatment path is described broadly below. The information pack then contains more detail on each option.

## SURGERY

### ❖ What treatments are available to help the baby?

The treatments available for each specific condition will be explained to you by the fetal and cardiac medical teams. A series of operations will be required, soon after birth and in early childhood. They are further described in detail in the 'Treatments' section of the information filofax.

### ❖ If we decide that we would like surgery, who will carry out the operation?

There will be a team of cardiac (heart) surgeons at the specialist centre where the surgery will take place. They work closely with the cardiologists (heart doctors) who made the diagnosis during your pregnancy and a team of children's nurses who specialise in caring for babies and children who have heart abnormalities.

It is often possible to arrange for you to visit the hospital where the surgery is planned during your pregnancy. This can be extremely useful as it means that you will be familiar with the intensive care unit and the wards where your baby will be treated. Ask the team who have made your diagnosis for more information.

### ❖ Will we have to travel to receive treatment?

As this type of surgery is very specialised, there are only a small number of children's heart units in Great Britain that have teams with the expertise needed to carry out these operations. It may be necessary to travel to ensure that you receive the highest quality of care.

Following discharge after surgery it may be possible for ongoing medical care to take place in a hospital closer to home.

### ❖ What are the risks of surgery?

It is important to remember that each and every child is unique and that although the medical team will be able to give expectant parents an idea of the national statistics and unit statistics for surgical success, they may quote a higher or lower risk for each individual child.

### ❖ Can the baby have a heart transplant?

Heart transplantation is one of the possible treatments for single ventricle heart disease, but it is not offered as a first treatment within the United Kingdom for the following reasons.

- There are very few donor hearts small enough for a baby available in the United Kingdom.
- Transplanted hearts do not last for ever and there are many risks involved throughout the recipient's life.

Offering surgery as a first treatment path and retaining transplant as a future option, offers a greater chance of a longer life for the child.

## TERMINATION (abortion)

For some parents the knowledge that even following repeated surgery, their child's heart and lifestyle will never be normal, means that they choose to end the pregnancy before the baby is full term: a termination.

### ❖ Am I allowed to terminate the pregnancy at this late stage?

In accordance with the law, it is possible to terminate a pregnancy at any point during the 40 weeks if the baby has a condition that would cause serious

handicap. This type of extremely serious heart condition would come into this category.

For more information on termination look at the section on ending the pregnancy.

## COMFORT CARE

Some parents feel that they could never contemplate ending a pregnancy, but do not feel that they want their baby to go down the surgical route of treatment. In these cases, 'comfort care' for the baby can be offered. This may be explained as "letting nature take its course".

### ❖ What happens to the baby if we don't want surgery?

If you have decided that you do not wish your baby to have surgery, it is very important that you have time to care for your baby for the duration of your baby's life.

You will be given as much support as possible to enable this to happen from the specialist baby doctors (paediatricians) and their team of nurses on the neonatal unit. These doctors and nurses are skilled in providing tender loving care for babies to keep them comfortable and in supporting parents through this difficult time.

### ❖ How long will our baby live?

Each family will be given a slightly different answer to this question.

Some babies depend on the circulation that they have inside the womb to keep them alive. As this circulation changes after birth, (see Fetal Circulation section), their hearts will no longer be able to supply their body with oxygen and they will die, usually within the first week.

Other children born with only one ventricle will be able to live for longer. The effects of their type of heart defect will slowly affect them.

Your medical team will be able to offer you more information about what would happen to your child if you choose this treatment path.

The next page shows some parents' experiences.

"When we first had the diagnosis, we wanted to 'unlearn' what we had found out - we didn't want to be faced with the kind of decisions we had to make. But with hindsight, we are glad we knew. It changed my focus throughout the rest of the pregnancy - my own little aches and pains became less significant - they were nothing compared to what our baby would have to go through. I am also convinced that Matthew would not be with us today without having had an antenatal diagnosis. He was very unstable at birth, so I am sure he would not have survived the hospital transfers (from somewhere without paediatricians, where he would have been born, to a hospital with a neonatal unit, followed by another transfer to a children's hospital where the cardiologists were based) and the delay of trying to find out why he was unwell."

"Having Thomas at home meant that our other children were able to get to know him and help with his care. They only knew him for a short time, but it definitely helped them to have some very special memories of their brother and meant we could all talk about these memories together.

The community nurses from the neonatal unit and our GP visited regularly and made sure that we felt supported and comfortable with his care. We knew we could always contact them or the neonatal unit if we had any worries."

"Knowing that I have translocated chromosomes I know when I get pregnant there is a 50 percent chance of me miscarrying. I usually only had to get past the 12-week mark for the baby to survive. So when I fell pregnant with my third child Rupert I was delighted to get past the dreaded 12-week period with no signs of losing him. I went along to my 21-week scan confidently, with my other two children in tow. It was then I was told that there might be a problem with the baby's heart.

Adrian and I went along the next day to a cardiac scan and we were told that Rupert had Hypoplastic Left Heart Syndrome and that he was going to be a very poorly child with a severely limited life expectancy. My catholic upbringing jumped in and I automatically thought "well it doesn't matter I still want him and we will care for him no matter what". Adrian had other thoughts and we went home and discussed it at length. Adrian had listened carefully to what the doctors had said, the baby was going to have a limited life expectancy and the quality of his life would be very poor.

I realised, in the cold light of day, that if I was to go full term with Rupert our whole family's life would be affected considerably, not just mine and Adrian's but also the lives of our two very active older children. Their lives would be put on hold and our whole family would all be waiting for a time when Rupert wasn't here any more.

It was extremely difficult at the time, but I have never regretted my decision, it was the right one to make not just for me but also for my whole family."

## CONTINUING WITH THE PREGNANCY

If you choose to continue with the pregnancy, there are many aspects of the delivery and treatment of the baby to consider. The following section explores this area of care but it is very important to talk to your obstetric and cardiac team to clarify what care is planned for you and the baby.

### ❖ Where will I have the baby?

Your baby needs to be delivered in a hospital which has a Neonatal unit where a specialist team can carry out the immediate care that your baby will require after birth. This team will also organise the safe transfer of your baby to the children's heart unit.

If the hospital where you initially booked to have the baby is a small district hospital they may not have these facilities. It may therefore be necessary to transfer your obstetric care to a unit which has these specialist services.

When an abnormality is found in a baby, the focus of attention for you and the health-care professionals shifts towards the baby. It is very important that the needs of the mother are not forgotten. All the normal antenatal check-ups should proceed as planned either with your midwife, GP or at the hospital.

There may be extra scans arranged at the specialist unit to monitor the baby's condition and often parents find these consultations stressful, as they wonder if further problems may be detected. You may find that the Specialist Midwife attached to the Fetal Cardiology service/Fetal Medicine department is a valuable source of support and can help you with the ongoing concerns you have about the pregnancy and birth. They will also be able to liaise between the Cardiac Liaison Team from the heart unit, your own hospital and your GP/Community Midwife to ensure that all carers are kept up-to-date with information about the baby's condition.

## PREPARING FOR THE BIRTH

Many parents feel increasingly anxious as they approach the time of delivery. Mothers often express how they feel protective of their unborn baby, knowing he or she is safe inside them. Facing the reality of what their baby will go through after birth is a daunting prospect over which they have little control.

Once again, being able to talk through these feelings with your midwife/GP/obstetrician can be helpful.

### ❖ Will I need a Caesarean section?

Many parents, understandably, think that because the baby has a heart problem, a Caesarean section would be the safest way to deliver the baby.

In fact, for most mothers, the opposite is true for the following reasons:

- Whilst the baby is in the womb, it is receiving all the oxygen it needs from the mother via the placenta (afterbirth) and this continues throughout labour until the baby is born and the cord is cut.
- Being born naturally allows the baby's chest to be squeezed as it comes through the birth canal. As the baby is born the release of pressure on the chest encourages the baby to take a deep breath and this helps the lungs to expand.
- You will want to spend as much time as possible with your baby in the time leading up to the first operation and your recovery following a normal vaginal delivery will be much quicker than following a Caesarean section.

During labour your baby's heartbeat will be monitored. If there are any signs of distress, or if there are problems for the mother, a Caesarean section may become necessary.

Some mothers do require Caesareans because of problems that they have had with a previous delivery or because of a problem with the size of their pelvis or birth canal.

If this becomes necessary the maternity hospital will link with the cardiac team to ensure that the mother has as much contact with the baby as possible.

**The most important thing to remember is that the mother and baby are kept as well as possible.**

### ❖ Will I need to be induced?

It is preferable for your baby to be born at the end of pregnancy, when it is well grown and the lungs are mature, and you go into labour naturally.

Prior to 34 weeks of pregnancy, the baby's size in conjunction with immature lungs, may mean that surgery is not possible.

It may be necessary to induce labour for the following reasons:

- If you have gone past your expected date of delivery.

- If your blood pressure rises and it is felt that it is safer for the baby to be delivered.
- If the baby stops growing.
- If you are delivering your baby at a unit which is some distance from where you live, it may be easier to plan a date for induction of labour, after the 39th week of pregnancy. This can be planned in liaison with the neonatal unit and the specialist cardiac unit, to ensure cots are available.

### ❖ Can my partner be with me when I have the baby?

Your partner/other family or friend will be able to be with you throughout labour and the delivery.

If you need to have a Caesarean section, your partner will be able to be with you if you choose to be awake and there is time to insert a spinal anaesthetic. Spinal anaesthetics are commonly used for Caesarean sections and this allows the procedure to be pain-free, but enables parents to share the moment of birth together.

Some women prefer to be asleep (have a general anaesthetic) for a Caesarean section. If the baby becomes distressed, the Caesarean may have to be done as an emergency procedure under a general anaesthetic, because there is no time to insert a spinal anaesthetic. In these instances, your partner will wait in the recovery room. Once the baby is safely delivered, as long as he/she is stable, your partner will be able to hold your baby whilst the operation is completed.

### ❖ Will I see the baby after he/she is born?

The baby should be in good condition at birth as the connection (Ductus Arteriosus) between the Pulmonary Artery and the Aorta does not close immediately. A Paediatrician (baby doctor) will be on hand at birth to assess the baby's condition.

If the baby is stable, there should be no reason why you should not be able to hold and cuddle your baby and put the baby to the breast if that is your wish.

After a short while, the baby doctors will want to take the baby to the neonatal unit, to insert a drip (infusion). In the case of babies dependant on the fetal circulation, this enables the baby doctors to give the hormone Prostaglandin, which keeps the Ductus Arteriosus open and allows the baby to remain stable until they receive their first surgical treatment.

### ❖ Who will be looking after the baby?

The paediatrician and nurses in the neonatal unit will be caring for your baby and making sure that the baby's condition remains stable.

A scan of the baby's heart will be carried out in the first few hours following delivery by one of the specialist cardiologists from the children's heart unit. On the basis of this assessment, surgery can be arranged and at every stage the doctors will discuss the plan of care for the baby with you.

Your partner and immediate family - other children and grandparents - can visit the baby on the neonatal unit and depending on how you feel after the birth, you will be able to spend as much time as possible with the baby.

### ❖ If the baby has to be transferred to a specialist heart unit, can we go with him/her?

You will be encouraged to go the children's heart unit with your baby, although the baby will travel by ambulance with medical staff if the heart unit is in a different hospital.

If you are well enough to be discharged you may follow the baby in your own car or the hospital will arrange transport if you are still a patient.

## FEEDING

### ❖ Will I be able to breastfeed the baby?

Once the newborn baby's condition has been assessed and if they are found to be stable it may be possible to put the baby to the breast soon after delivery. Once the drip has been inserted and the baby is receiving the Prostaglandin to keep the duct open, as long as the baby is stable, it may be possible to breastfeed up to the time of surgery. From then on you can use a breast pump to express milk. The milk can be stored safely and then can be given to the baby either through a naso-gastric feeding tube or eventually a bottle.

Although breastfeeding will be encouraged, it is important to realise that feeding will be very tiring for the baby. To help support their heart function, they will need to have more calories than other babies, but they do not always have enough energy to take all the milk that they need. Often a mixture of feeding styles may be needed. For example, bottle or breastfeeding, calorie additives and naso-gastric feeding (a tube from the nose into the stomach) will ensure that the baby receives enough calories to grow.

If you are keen to breastfeed, ask for support from the hospital team and your visiting midwife. It may also help to talk to other parents who have successfully breastfed a baby with complex heart disease. This can be done through the hospital or through Little Hearts Matter.

### ❖ Who looks after the mother after the birth?

It is important that after the delivery the mother's medical needs are not forgotten in the midst of all the care being organised for the baby. Before the mother can be discharged from the maternity unit she will be examined by one of the obstetric team at the maternity unit. She will then be transferred to the care of either her home based community midwife or the community midwife who covers the children's cardiac unit. A new mother needs regular check-ups from the midwife. If there are any concerns about her condition whilst at the children's unit, a midwife will be called and any hospital care will be organised at the closest maternity unit.

Although the mother is worrying about the baby, she must organise plenty of rest for herself and eat regularly. She needs to recover well from the delivery so that she has the energy to look after the baby once they are discharged home.

## ENDING THE PREGNANCY (TERMINATION)

### ❖ What would termination involve at this stage of pregnancy?

As most diagnoses of complex heart disease are made after the 20th week of the pregnancy it is important to think about the method of termination that would be needed.

At this stage of pregnancy the only way for the pregnancy to be terminated is to deliver the baby. Labour will be induced and the baby will be delivered vaginally. It is a difficult prospect to imagine going through a labour and parents often ask why the baby can't be born by Caesarean section. There are risks to the mother associated with Caesarean section and so it is felt that the safest way to deliver the baby is to have labour induced with all methods of pain relief being available. Usually the baby will be born within 6 - 8 hours.

Your obstetrician will discuss specific details about your individual circumstances with you.

### ❖ What will happen to my baby at delivery?

Most parents feel apprehensive about the birth and the midwives caring for you will talk to you about your concerns. You will be given a choice as to whether to see and hold your baby and this is a very individual choice. Many parents have found that seeing and holding the baby, enables them to have very precious and real memories of the baby, and this has helped them in coming to terms with their loss. Most hospitals will take photographs and make a remembrance folder of the baby, which will be kept in your hospital file if you do not wish to see the baby at birth. Some parents choose to take photographs of their baby with their own camera.

### ❖ What happens to our baby after we leave hospital?

Following the birth you will be visited by a member of staff responsible for bereavement services and they will discuss with you what your individual wishes are regarding funeral arrangements. The hospital will do its best to accommodate any religious or cultural beliefs the parents wish to be observed. It will be your individual choice as to whether you wish your baby to be buried or cremated. Hospitals can make all the necessary arrangements for the baby to be cremated or buried, however some parents prefer to make their own private arrangements for a funeral. This member of staff will also inform you of the legal requirements surrounding registering the baby.

Following the birth you will be asked whether you would wish your baby to have a postmortem. It is another very difficult decision for bereaved parents to face, but it can give additional answers which otherwise would not be known.

### ❖ Will this happen to us again?

Following a termination, the question uppermost in parents' minds is, "will this happen again in a future pregnancy?". To answer this accurately a number of essential pieces of information are required and a postmortem may be the only way to complete the jigsaw.

If the heart condition is associated with other abnormalities or problems in the baby's genetic make-up, then the risks of this happening again may be higher than if we know that the heart condition is the only problem the baby has.

If the obstetric team feel that there is a high risk of a recurrence they may refer a family to the Genetics team who will look into the family history of congenital problems and will then draw up a risk assessment for an individual family. This is known as genetic counselling.

### ❖ If I terminate the pregnancy can I have other children?

Terminating your pregnancy for abnormality will be a physically and emotionally traumatic experience for you, however it should not mean that you cannot have other children.

There are few physical risks associated with termination and women usually recover relatively quickly.

The emotional effects of termination vary for each individual and you need to grieve for your baby in your own way and time and this may affect your decision of whether or when to try for another baby.

#### Associated physical risks:

- Retained placenta (afterbirth) which may require removal under general anaesthetic.
- Prolonged bleeding - may be due to retained placental tissue and may require a small operation known as an 'evacuation of retained products' to stop it.

## COMFORT CARE

### ❖ If I choose comfort care as my treatment choice what sort of delivery will I have?

The delivery can be the same as for any other baby. The obstetrician and midwifery team caring for you during your pregnancy will discuss your wishes with you prior to delivery. There need be very little monitoring and in most cases, a Caesarean section would not be necessary unless the mother showed signs of physical distress.

It would still be very important that the mother and father felt involved with the birth and that they have the opportunity to make the delivery as memorable as they wished.

#### Caring for your baby in hospital

- After the birth of a terminally ill baby families may wish to stay in the hospital until the baby dies. They will be surrounded by a caring team who will support the family through the days after the birth.
- You would be accommodated in a single room with your baby in the neonatal unit so that you can be directly supported by the staff.
- Most parents are concerned that their baby might suffer or be in pain. The doctors and nurses will ensure that the baby is kept comfortable and will support you in giving whatever care is necessary for the baby.
- Friends, relatives and other children would be able to visit freely.
- During this time parents would be encouraged to build memories of the baby through the taking of photos and the collecting of mementos.
- Representatives of religious faiths can visit and services can be held at the hospital.
- The main aim of this special time is to allow families to be as involved with their child as they would like, whilst ensuring that the baby is comfortable. The hospital bereavement team will be at hand to offer help and support both before the baby's death and in the days after.

## ❖ Who will help us if we want to take the baby home?

On occasions some parents wish to care for their baby at home and they will be supported by the community neonatal nurses in liaison with the doctors from the neonatal unit.

In some areas of the country there are specialist teams of doctors and nurses sometimes linked to a children's hospice who support parents who wish their baby/child to die at home. The staff on the neonatal unit where your baby will be initially after birth will be able to give you information about how care is provided in your individual area.

Parents who have chosen to do this have felt that it has given them the opportunity to look after their baby in the more relaxed environment of their own home.

Following the baby's death, parents will be given the opportunity to discuss their wishes about funeral arrangements with their local funeral director and any religious groups that they are involved with.

## FUTURE PREGNANCY

### ❖ What are the risks of having another child with the same problem?

In any pregnancy there is a 1% chance of a baby having a heart problem.

If you have had a previous child with a heart abnormality, the risk of a further child having a heart problem is approximately 3 - 5%. This is known as the recurrence rate.

There is a wide spectrum of heart abnormalities from relatively minor holes in the heart or heart murmurs, to the extremely complex problem your baby has.

The 3 - 5% risk encompasses the whole spectrum of heart abnormalities, but it is rare to have another baby with the same problem.

**REMEMBER THE RISKS ARE STILL SMALL.**

**95 - 97% OF PARENTS WILL HAVE FURTHER CHILDREN WITH COMPLETELY NORMAL HEARTS.**

When planning a future pregnancy it may be useful to discuss your risks and ways for you to stay healthy with your GP, obstetrician or a special midwife. This is known as pre-natal care (before the baby is conceived).

### ❖ Will we be able to have any extra scans to reassure us?

Understandably, you will be very anxious that the condition may be present in a future pregnancy. Currently there are no blood tests available to indicate a heart problem. The first time that a problem could be detected is between 14 and 20 weeks. Your local obstetrician should arrange for a specialist cardiac scan with the local Fetal cardiac team. This may seem a long way into the pregnancy, but the baby's heart needs to be a reasonable size to be able to see all of the heart's chambers, valves and main blood vessels. At twenty weeks the heart is approximately the size of a small walnut.

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This DVD contains further information from clinical specialists about antenatal diagnosis but more importantly the views and personal experiences of families and children affected by single ventricle heart disease.

There may be chapters of the DVD that you would rather not watch, choose from the DVD menu the areas you are interested in exploring.



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