

# Giving birth at St Thomas' Hospital when your baby has a heart condition

This information is about giving birth at St Thomas' hospital when your baby has a heart condition and the care your baby will receive at Evelina London Children's Hospital.

# How your care will be transferred from your local hospital to St Thomas' Hospital

If your baby has been diagnosed with a heart condition, you and your local obstetrician might have agreed that you should give birth at St Thomas' Hospital, so your baby can be cared for at Evelina London Children's Hospital.

The tower team midwives are a group of midwives who care for pregnant women and babies that need specialist care. They provide care in partnership with a fetal medicine obstetrician, who is also based at St Thomas' Hospital. They will contact you to arrange an appointment.

You will be given appointments with both a tower team midwife and the consultant obstetrician on the same day. We also offer a phone appointment if we cannot book you in for both appointments on the same day. If this happens, the bloods, observations and urine (pee) tests will all be done in the fetal medicine unit. These appointments will take place on the 8<sup>th</sup> floor of North Wing, at St Thomas' Hospital. Please bring your maternity notes with you.

#### Your appointment with the tower team midwives

During your appointment, a tower team midwife will look at your medical and maternity history. You will also have routine antenatal blood tests. There will be an opportunity to discuss your care during your delivery and your birth plan, which will depend on your own medical history and your own choices. Usually your baby's heart condition would not affect the type of delivery you can have.

This appointment will last about 90 minutes, so please take this time to discuss any anxieties or questions you have.

Please note the tower team midwives cannot answer questions about your baby's treatment **after you have given birth**. These questions should be directed to the fetal cardiology clinical nurse specialists. Please see page 7 of this leaflet for contact details.

# Your appointment with the consultant obstetrician

During your appointment, your baby will have a complete body scan. At this appointment you might be given a date for your planned induction of labour. You can read about this in the 'Your birth experience' section below. If we cannot give you a date at this appointment we will plan to discuss this with you at another time.

# After your appointments

After you have had these appointments, there are 2 options for continuing your midwifery care. The choice is yours, but it is important to consider the travel time to St Thomas' Hospital. We will let you know if we feel that you should continue to have all of your appointments with us. Your local team can often continue to provide the care you need.

## Transferring all your care to St Thomas' Hospital

All of your care could be transferred to St Thomas' Hospital so that your remaining midwife, doctor and scan appointments will take place there. Appointments will take place every 2 to 4 weeks until the birth of your baby.

For more information about maternity care at St Thomas' Hospital visit web www.guysandstthomas.nhs.uk/our-services/maternity-care-during-pregnancy

### Continuing your care with your local team

Alternatively, you can continue to see your local midwife and obstetrician until you come to St Thomas' Hospital to have your baby.

# **ECHO** antenatal education day

The Evelina Children's Heart Organisation (ECHO) supports our service by sponsoring an antenatal education day for parents expecting a baby with a heart condition. It is run by the tower team midwives every 6 weeks on a Saturday, online via Zoom. During the session, you will receive information about how you can best prepare for the birth of your baby, and postnatal care.

It is an opportunity to speak to other parents who are having their baby at St Thomas' Hospital.

An ECHO parent will also talk to you about their journey from diagnosis to present day. They are a parent volunteer who has a baby with a heart condition.

When you are contacted by the tower team, please let them know if you want to attend these sessions, and they will book you a place.

# Your birth experience

Your baby's heart condition should have very little impact on your birth choices. However, most parents live some distance from St Thomas' Hospital and it would not be safe for you to travel to the hospital during labour. Because of this, we might offer you a planned induction of labour between 38 and 39 weeks of pregnancy. Having a scheduled delivery also allows us to plan for admitting your baby to the neonatal unit (NNU). We will give you information about this process during your tower team appointment and during the ECHO antenatal education day.

Although we cannot give you a date for your induction, we sometimes need to delay the date because of the availability of cots in the NNU, or beds in the **hospital birth centre (HBC).** This is because we cannot predict how busy the hospital will get. For this reason, we ask you to stay at home until you have been told to come in by either a member of the tower team or a midwife from the HBC. In the HBC, you can have 3 named birth partners, although only 2 of them can be in the birthing room at the same time.

If you are showing any signs of labour, have any vaginal bleeding or notice a reduction in your baby's movements before your admission to St Thomas' Hospital, you must go to your local unit for assessment - even if your care has been transferred to St Thomas' Hospital.

If it's unsafe to transfer you to St Thomas' Hospital, and your baby is born in your local unit, the paediatric cardiology team at the Evelina London Children's Hospital will be contacted by your local unit and arrangements will be made to transfer your baby. The obstetric and midwifery teams will arrange a separate transfer for you, and we try to reunite you with your baby within a few hours.

# After your baby is born

We try to give all babies delayed cord clamping, which is when the umbilical cord is not clamped immediately after birth. This means they can benefit from as much of the circulating blood flow from your placenta as possible. During this time, you will be able to have skin-to-skin contact with your baby.

The neonatal team will check your baby in the delivery room. If everything is OK, you should be able to have another cuddle with your baby before they are transferred to the NNU. This will depend on your baby's condition and the type of monitoring they need to make sure they are safe. When your baby is transferred to the NNU, your birthing partner can stay with them.

When the midwife caring for you is happy with your observations, blood loss and mobility, you will be able to see your baby in the NNU. We aim to get you to your baby as quickly as possible, but mothers do need some recovery time after the birth, and need to be monitored. If you have had a vaginal birth with no complications, we can take you to the NNU about 1 hour after the birth. If you have a caesarean section or any complications, you will need to wait at least 8 hours to recover.

When it is safe, you will be taken to the postnatal ward to recover. This is on the 6th floor of the North Wing, opposite the NNU. We aim to offer you a single room for your stay here, but this is not always possible. You can have 1 birth partner to stay overnight with you in a reclining chair next to your bed. The postnatal ward midwives will be in charge of your day-to-day care. The tower team midwives will also aim to see you each day to make sure you have everything you need.

How long you stay on the postnatal ward will depend on your birth. Once you are well enough, you will be able to go home.

For more information about the postnatal ward at St Thomas' Hospital visit web www.guysandstthomas.nhs.uk/our-wards/postnatal-ward

# How your baby will be cared for

Babies with a heart condition are cared for in a Babytherm® bed. They are only placed in incubators if they are born prematurely. The Babytherm bed helps regulate (control) the baby's temperature. In most cases, they will not need to be fully clothed and only need to wear a nappy and a hat.

The number of tests and amount of monitoring your baby will need will depend on their medical condition. The need for any tests will be explained to you by a member of the team taking care of your baby. You can speak to the team looking after you if you are unsure of anything. Your baby will be placed on a heart monitor and will have the amount of oxygen in their blood measured with a pulse oximeter. This will not cause your baby any discomfort.

A medical assessment will need to be done before your baby can have their first feed. There might be times when baby is unable to feed by mouth and a naso-gastric (NG) tube might be needed. An NG tube is a soft, thin, plastic tube that is placed through their nose and into their stomach. The tube is secured with a small piece of tape to their cheek. Your expressed breast milk can be given in this way and the staff can support you in expressing milk.

Your baby might need to have an intravenous (IV) line inserted. This helps us give your baby any medicines they need. It can also be used to give your baby fluids if they cannot feed.

Sometimes, babies need help with their breathing. If this happens, an endotracheal tube (ET tube) will be used. This is a tube that is placed in your baby's airway through their mouth or nose, and a ventilator will help with their breathing. Your baby may be sedated to prevent discomfort.

# Where your baby will be cared for

This will depend on your baby's diagnosis and their plan of care. Your baby will be taken to the NNU first.

# **Neonatal unit (NNU)**

The NNU is a ward that is divided into 3 areas of care:

- neonatal intensive care unit (NICU)
- high dependency unit (HDU)
- special care baby unit (SCBU)

For more information about these areas please see the **neonatal unit welcome booklet**.

Your baby's daily care will be led by the consultant on-call during the admission to the NNU. They will work closely with the consultant neonatologist, who is a specialist doctor that cares for new born babies. If your baby does not need treatment immediately, or if they have been observed in NICU or SCBU for some time, they might join you on the postnatal ward and can go home if they are well enough.

The NNU is committed to making sure you are at the centre of your baby's care. The team will involve you in discussions about the treatment and care your baby will need. They will support you to be as involved as possible at all times.

Parents are welcome on the NNU at any time. There can only be 2 visitors at the bedside at the same time. Your baby's siblings (brothers and sisters) are welcome to visit with you, but other children under the age of 16 years are not able to visit the NNU. Friends and family can visit between 4pm and 7pm. You can speak to the nurse in charge if you have any questions about visiting times.

The children's cardiology consultant who is on-call when your baby is born will be your baby's consultant for future outpatient appointments.

#### Paediatric intensive care unit (PICU)

Your baby might be transferred to PICU on the 2nd floor of Evelina London. If your baby has surgery, they will be taken to the PICU afterwards. Depending on their diagnosis, they might also need to be taken to the PICU before having surgery. How long your baby needs to stay here will depend on their condition. Parents can visit their baby on PICU at any time. Siblings can visit during visiting hours only.

#### Sky ward

After your baby has had heart surgery and has been taken to the PICU, they could be transferred back to the NICU or might be taken to Sky ward (the inpatient children's ward on the 4th floor of Evelina London). This transfer could also take place during the waiting period before surgery. Parents can visit their baby on Sky ward at any time. Siblings can visit during visiting hours only.

# **Breastfeeding**

Breastfeeding is promoted by all of the teams involved in your baby's care. If your baby is unable to feed by mouth, an NG tube will be used. Your expressed breast milk can be given to your baby this way. The staff on the postnatal ward, NNU, PICU or Sky ward can help you with this. Each of the wards has breast pumps and private areas to help you in expressing for your baby. The midwives on the postnatal ward will be able to get you started with this and provide you with storage advice. The tower team also speak to you about this at your appointment, and at the ECHO antenatal class.

# What to bring for your baby

You will need to provide nappies and cotton wool in the NNU. You can also bring a baby blanket and a few small toys. We suggest sleeping with the blanket and toy in your bed before giving birth, so that it has your smell, which will comfort your baby when you're not with them. Some families like to personalise their baby's bed space by bringing in family photos. You can also have a religious item if you want.

Babies with heart conditions can benefit from having a dummy. Babies have a strong sucking reflex from birth, but often feeding is restricted for medical reasons. The use of a dummy can soothe and comfort when a baby is not feeding by mouth. This is your choice and they will not be used without your permission (consent). The hospital can supply 1 type of dummy, but it is helpful if you can buy others and bring them to the hospital with you. There are facilities to sterilise dummies in each of the wards.

# Staying at the hospital

Babies usually need to stay in hospital longer than their mothers. If this is the case, we will aim to provide you with accommodation close by, or you might prefer to return home and travel to the hospital each day to be with your baby. There are several options for accommodation when your baby is being cared for in hospital.

#### Ronald McDonald House (RMH):

Accommodation at the RMH is provided to families that are living outside the M25 and have a baby or child as an inpatient at Evelina London. This accommodation is free of charge, although a key deposit (about £25) is needed when you check in. RMH is about a 5-minute walk away from Evelina London. There are 59 rooms available. A waiting list system is in place and families that live furthest away are given priority.

It's not guaranteed that accommodation is available for siblings, and this will be discussed caseby-case. Your name will be put on the waiting list by the tower team midwives once your baby is born, if appropriate. The nurses caring for your baby will update you when a room is available.

For more information about Ronald McDonald House visit web www.rmhc.org.uk

If your baby is being cared for in the PICU (paediatric intensive care unit), the PICU team will try to provide you with family accommodation on the 1st floor of Evelina London if available.

If your baby is being cared for on Sky ward (6<sup>th</sup> Floor, Evelina London) 1 parent will be able to stay with your baby. A pull-out bed is supplied next to your baby's cot. You can continue to stay at Ronald McDonald House if your baby is in the high dependency section of Sky ward.

# Car parking

Parking is very limited at St Thomas' Hospital. The car park is 'pay on exit,' which means you need to pay and get your exit ticket before returning to your car. If you pay by cash, please have the correct change. You can also pay by credit or debit card. The car park is open 24 hours a day. Disabled patients coming to an appointment will be allowed free parking. Disabled visitors do not qualify for free parking.

When your baby is an inpatient at Evelina London, a weekly car-parking permit can be organised by the security team at a charge of £25. Speak to the nurse in charge of the inpatient area to organise this.

St Thomas' Hospital is located in the London Congestion Charge Zone and Ultra Low Emission Zone (ULEZ). For information on Congestion Zone and ULEZ charges visit the Transport for London website web https://tfl.gov.uk/modes/driving/

# Other things to consider

#### The personal child health record (red book)

You will be given a personal child health record (PCHR). This will be given to you by the HBC staff during your admission or when you are discharged. This usually has a red cover and is often called the 'red book'. It is an important way for you to keep track of your child's health and progress, and for sharing information with health professionals involved in your child's care.

#### Registering your baby's birth

You must register your baby's birth with the local registrar where the birth took place. This must be done within 42 days of the child being born. You will receive your baby's NHS number from the midwives on the postnatal ward and you will need this to register the birth.

If your baby is born at St Thomas' Hospital you should plan to register the birth with the Lambeth registry office at Lambeth Town Hall. If you can't come to that office, you can give the birth details to your local register office. They will send the information to us, and the Lambeth office will send the birth certificate and other documents in the post to your home. To register at the Lambeth offices, please make an appointment after you have given birth, phone 020 7926 9420. For further details about registering a birth visit web www.gov.uk/register-birth

# Registering your baby with a GP

You should register your baby with a GP before they are discharged from hospital or soon afterwards. It is important to do this so you can get your baby appointments or follow-up prescriptions without delay. The GP will also be needed for your baby's routine 6 to 8 week postnatal health check.

#### Your health visitor

Before your baby is born, speak to your community midwife, tower team midwife or fetal cardiology clinical nurse specialist (CNS) about meeting with a health visitor. Your health visitor will be a registered nurse who will provide support for the general health needs of your baby. They will visit your home and provide information on the baby clinic that you can attend to get your baby weighed. They also provide the necessary immunisations for your baby. They are a valuable source of support and can work with the Evelina London team.

#### **ECHO (Evelina Children's Heart Organisation)**

Provides support and information for parents expecting a baby with a heart condition web www.echo-uk.org

#### Contact us

If you have any questions or concerns about your birth, please contact the tower team midwives, **phone** 07717 700 276 (24 hours).

If it's an emergency and the call is not answered, please contact the hospital birth centre, **phone** 020 7188 2975 or 020 7188 6867.

For ongoing support related to your baby's heart condition, please contact the fetal cardiology clinical nurse specialists (CNS), **phone** 020 7188 2308, 07918 338 959 or 07831 149 785, Monday to Friday, 9am to 5pm.

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit web www.evelinalondon.nhs.uk/leaflets

#### **Evelina London Medicines Helpline**

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

phone 020 7188 3003 10am to 5pm, Monday to Friday

#### **Language Support Services**

If you need an interpreter or information about your care in a different language or format please contact the department your appointment is with.



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