Pregnancy

Somerville Heart Foundation

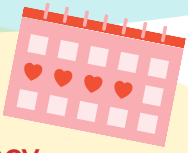
Adult Congenital Heart Disease

ACHD

For young people and adults born with a heart condition

Congenital Heart Disease

Congenital heart disease (CHD) occurs in 8-9/1000 of all live births, which means that roughly 1% of the general population will have a heart condition that they were born with. CHD is an umbrella term describing heart conditions present at birth. The complexity of the heart condition can vary greatly and the experience of living with CHD will be very different for each person, depending on their condition and what, if any, treatments have been needed.



Planning Pregnancy

Pre-conception counselling

Pregnancy increases the amount of blood circulating in your body by approximately 50%, and this can be even higher if you are pregnant with twins. This extra workload on the heart means it is important to have a check-up and a specific discussion before you embark on pregnancy.

It is important for you to know if and how your heart will cope with pregnancy and it's best to discuss this with your cardiologist well in advance of considering pregnancy, just in case additional tests are needed.

Pre-conception counselling is a way of discussing pregnancy and its risks with your specialist prior to falling pregnant, so that you can make an informed decision about having a baby and how this might affect your heart. For some, the physiological changes of pregnancy increase the risks to the woman, so it's a good idea to ask your GP or cardiologist to refer you to a specialist maternal cardiologist to have these discussions.

Medications

Some commonly prescribed medications can be harmful to a developing baby. If you are taking medications, it is important to check if you can continue or whether you need to stop them before trying to get pregnant. Medication may have to be stopped/changed or replacement medications may need to be started.

If you are advised to stop a particular medication you may be invited back to clinic a few weeks later for a heart scan and/or to see if you have noticed any change in your symptoms. Common medications that need to be stopped during pregnancy are angiotensin converting enzyme (ACE) inhibitors (e.g. Ramipril), angiotensin receptor blockers (ARB) (e.g. Losartan), Amiodarone, and blood thinners such as Warfarin.

If you are taking Warfarin, you are likely to be advised to stop this soon after becoming pregnant (often before six weeks of pregnancy) and replace it with a daily injectable blood-thinner for the duration of pregnancy. If it is recommended that you use an injectable blood thinner you will have close monitoring by the haematologist every few weeks throughout pregnancy.

The Obstetrician

Whilst your cardiologist is the expert who looks after your heart, your obstetrician is the expert who looks after your pregnancy and baby. It is important to see a team of doctors who have a good understanding of CHD. It might be appropriate for you to see your local cardiology and obstetric teams. However, your maternal cardiologist might recommend that you are seen at a specialist centre in your region.

Your CHD or maternal cardiologist will be able to advise on this and it is part of the information you will receive at your pre-conception counselling appointment.

To make sure they are able to provide the best care for you and your baby, your obstetrician will need as much information as possible about your heart. It is important to inform your cardiology team of the name of your obstetric consultant as soon as possible so that your clinic letters and test reports can be sent to them, as well as to you and your GP.

Both the obstetrician and cardiologist are there to ensure you have a safe pregnancy. However, your baby's health is closely intertwined with your own, so maternal health (your health) is always the priority for the doctors looking after you. Your cardiologist and obstetrician will work closely together, and with you, to ensure you get the best care and outcome.

Finding Out You Are Pregnant

You should inform your GP as usual when you find out that you are pregnant. They will make sure that you see the midwives and obstetricians at the right time. You should also inform your cardiologist as soon as you find out that you are pregnant, and they will be able to tell you when and how often you need to be seen.

Some women might only need to be seen once by a maternal cardiologist during pregnancy, while others with more complex heart conditions will need to be seen more often. The frequency of reviews will be tailored to you and your maternal cardiologist will ensure you see any other specialists who need to be involved.

General Health

Looking after your general health is always important but is even more so during pregnancy. A healthy, balanced diet, avoiding alcohol and not smoking are all important for your own wellbeing as well as for the health of a developing baby. It is good to continue exercising; however, the demands of pregnancy might mean that you are more tired and breathless than usual so you may need to change your exercise routine depending on how you feel.

It is important to maintain excellent oral hygiene with CHD, to minimise the chances of any infection in the mouth travelling to the heart valves and causing a serious condition called endocarditis. To help with this, NHS dental care is free for the duration of pregnancy and for a year afterwards.

You will also be advised to take the usual folate pre-pregnancy and pregnancy supplements to reduce the risk of your baby developing neural tube defects such as spina bifida.

Clinical Nurse Specialists

Pregnancy with a heart condition can be a difficult time. There may be increased hospital visits and you may see more doctors than normal. It can be hard to make sense of what you're seeing each team for and how to fit this in to your life.

Most maternal cardiology services have a Clinical Nurse Specialist (CNS) or specialist nurse who is experienced in looking after pregnant women with heart conditions. They will be able to help you coordinate your care and answer questions. They are also there to report symptoms to if you feel there has been a change in your health. When you inform your maternal cardiologist that you are pregnant, you should make sure you know how to get in touch with your CNS.

High-risk Pregnancy in CHD

It is important to bear in mind that no pregnancy is without risk. However, for some women, their heart condition might mean that the risk to their health is very high. In these situations, your maternal cardiologist might advise caution, or even advise against pregnancy.

You might be advised that pregnancy would be high risk with the current state of your heart condition, but that it might be possible to reduce that risk by having an intervention. For example, a narrowed valve can be opened, or a leaky valve replaced.

In this situation, your regular cardiologist and your maternal cardiologist will work closely together to coordinate your care. Decisions about going ahead with pregnancy or not, when you have a heart condition considered high risk in pregnancy can be very difficult. It is important to make sure you have all the right information and support to help you make your choice.

Conditions Considered High Risk in Pregnancy

For women without heart disease there is a small risk of dying during pregnancy (1 in 20,000). For women with CHD this risk can range from less than 1% (1 in 100) to 50% (1 in 2). This is dependent on your own specific heart condition and is something that you should discuss with your cardiologist and raise at your pre-conception counselling review.

Conditions such as Eisenmenger's syndrome, pulmonary hypertension, cyanosis, severe obstruction of the aortic or mitral valves, enlargement of the aorta (aortopathy) or impaired pump function are considered high risk. However, the severity of any one condition does vary between individuals, so you do need an individualised risk assessment.

The Baby's Outcome

In the general population roughly 1% of babies are born with some form of heart condition. If you have a heart condition yourself, the chance of your offspring having a heart condition is usually 4-5% but for some heart conditions it is higher, and can be up to 50%. Because there is an increased risk of your baby having a heart problem, a foetal echocardiogram is performed between 18 and 20 weeks.

Most major heart problems can be detected on this scan, but some of the less complex CHD conditions might not be detectable until after birth. If a very serious abnormality is found, you will be counselled with regards to your options.

Some CHD conditions are associated with low oxygen levels or mean that the heart is able to pump less effectively. This can mean that the developing baby doesn't always get everything it requires to grow well. In this case you might be warned about having a small baby – often called intrauterine growth restriction (IUGR), or the baby may be born early (pre-term).

You may be advised that you will need to be very sedentary during pregnancy to maximise the baby's growth. This can be difficult for women who work or who have other children at home and you will need a lot of support during this time.

With good neonatal care many babies born pre-term can do very well. However, there is a risk that if a baby is born prematurely they may have lifelong healthcare needs. If your maternal cardiologist anticipates that your baby will deliver early (either as a precaution to protect your health or because your heart condition tends to cause babies to be born early) they will refer you to a neonatal specialist who will talk you through what to expect and the likely outcome for your baby.

Delivery and Post-Delivery

Will I need a caesarean section?

A vaginal delivery is safe for the majority of women with heart conditions and there is no automatic need for a caesarean delivery. However, there are sometimes obstetric reasons that mean a caesarean section is the preferred mode of delivery and there are also some heart conditions where a caesarean is recommended. These are discussions you will have over the course of pregnancy with your obstetrician and maternal cardiologist.

If your heart condition means there will need to be special instructions for your birth plan, such as increased monitoring, this will be discussed during your maternal cardiology appointments and will be communicated clearly to your obstetrician and midwives. It is important that you carry a copy of any delivery plans (both cardiac and obstetric) in your maternity notes.

When can I go home?

After giving birth, fluid shifts from the womb into the circulation. This is usually tolerated well but can cause an increase in symptoms, so it is sometimes necessary to stay in hospital longer than usual to make sure the fluid shift doesn't make you feel unwell.

Thrombosis (blood clots) is more common in pregnancy and after childbirth so, depending on your particular heart condition, you might need injections to thin the blood. Your cardiologist will advise if this is necessary.

Can I breastfeed my baby?

Some medications can be passed on to your baby through breast milk. It is important to check with your cardiologist if any of your medications mean you should not breastfeed.

Depending on your heart condition, it can be important for your circulation to make sure that you are well hydrated. This can be more difficult when breastfeeding as you lose a lot of fluid through your milk. Therefore it is important to make sure that you are drinking enough water during the time that you are breastfeeding.

After you have had your baby

It is NOT fussing to keep a careful eye on your health after giving birth – even if it feels like it. Possible problems like anaemia (low iron levels in your blood) or common infections could be serious for your heart condition. If you don't feel well (you have a raised temperature, chest pain, feel more breathless or develop swollen legs) you should call your GP or attend A&E.

After you have had your baby you will need one more appointment with your maternal cardiologist to check your heart. It is normal for the heart to change in size during pregnancy and it is important to make sure that things return to normal after the birth.

Your maternal cardiologist will tell you how many weeks after the birth they would like to see you, based on your individual heart condition. You may also have an echocardiogram at this appointment. After this review you will be referred back to your usual cardiologist. You will only need to see your maternal cardiologist again if you decide you would like to have another baby.

What Should I Ask My Cardiologist?

Family planning decisions can be difficult and emotional and it might be difficult to remember everything you'd like to discuss. It is often helpful to take a list of questions and concerns to clinic.

You might want to think about the following with your friends, family or partner:

- What are the risks to me?
- What are the risks to the baby?
- What is the risk of the baby inheriting a CHD?
- Should any of my medications be stopped or changed before becoming pregnant?
- Will I need to have any extra tests or procedures before trying for a baby?
- How often will I be seen during pregnancy?
- Will I need to see other teams during pregnancy?
- What type of delivery am I likely to have?
- Will I need to be in hospital for long before the delivery?
- Can I have a vaginal delivery?
- If it is safe for me to deliver vaginally, can I still have a caesarean section if I want one?
- Will I have to have an epidural?
- Will I need any needles or extra monitoring during my labour?
- Will I be able to hold my baby after delivery?
- Is there any kind of pain relief I must avoid because of my heart condition?
- Will I be able to breastfeed if I want to?

After the consultation you should have all the information you need to make a decision about whether and when to start a family.

Glossary

ACE – Angiotensin Converting Enzyme
ACEi - Angiotensin Converting Enzyme inhibitors
ARB – Angiotensin Receptor Blockers
CHD – Congenital Heart Disease
CNS – Clinical Nurse Specialist
Echocardiogram (echo) – ultrasound scan of the heart
Foetal echo – detailed ultrasound scan of baby's heart before birth
Health Visitor – healthcare professional specialising in the care of children between 28 days and 5 years old
IUGR – Intra-Uterine Growth Restriction
Maternal Cardiologist – doctor specialising in the care of women with heart conditions who are pregnant
Midwife – healthcare professional specialising in the care of women during pregnancy and women and babies in the first 28 days after birth
Obstetrician – doctor specialising in pregnancy and childbirth
Obstetric anaesthetist – doctor specialising in pain relief and anaesthetics during pregnancy and delivery
Neonatologist – doctor specialising in the care of babies immediately after birth

Further Information, Support & Membership

You never know when you may need some extra help or advice. It's free to join Somerville Heart Foundation at www.sfhearts.org.uk/sign-up/ to access our leaflets, newsletters, mental health & wellbeing services and much more.

We are a registered charity, reliant on donations, fundraising and legacies. It's free to join but not free to run - your donations ensure the future of ACHD support for years to come.

Somerville Heart Foundation

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