

The Somerville Foundation

Supporting young people and adults
born with a heart condition



GUCH and Pregnancy

It is a tribute to modern day infant heart surgery that those born with congenital heart problems can now consider having children themselves. Congenital heart defects (CHD) also known as GUCH (Grown Up Congenital Heart) complicate about 1 in 100 live births in the UK. Many of these heart defects are simple but about 40 percent are more complex, but thanks to advances in modern medicine most of these heart lesions are now treatable. This means those born with congenital heart problems become adults and have the opportunity to consider having a family.

If you have a congenital heart problem and wish to become, or you are already pregnant, there are specific issues you need to consider and be aware of. Hopefully the following information will be helpful to you.

> Planning pregnancy

The most important thing is the 6 P's;

Prior Planning Prevents Poor Pregnancy Performance

Ideally pregnancy in women with heart problems needs to be planned even before conception! Your fitness for pregnancy i.e. whether your heart will cope with the extra work that pregnancy places upon it, or whether or not it is safe for you to become pregnant, should be discussed in advance of becoming pregnant. Certain medications also need to be stopped prior to pregnancy and this should only be done in agreement with your specialist cardiologist.

The following sections highlight why planning for pregnancy is important.

> Discuss your plans for pregnancy with your Cardiologist & an Obstetrician

The Cardiologist

If you are considering becoming pregnant make an appointment to see your cardiologist. Your cardiologist is the expert and they will know the details of your heart condition. Pregnancy makes the heart work harder. The amount of blood in your circulation doubles and your heart rate and workload will increase.

Your cardiologist can explain to you the effect that pregnancy might have on your health. They may wish to perform an echo scan or exercise test, which will give them

an idea of whether your heart is "fit" enough for pregnancy. The cardiologist is there to advise you whether or not your heart will cope with the extra work placed on your heart and of the risks that pregnancy poses to your health.

They may wish to change or stop your medications as some may not be good for the baby. This should often happen before you are pregnant as sometimes you can be up to 6 weeks pregnant before being certain that you are pregnant. The most common cardiac medications which tend to be stopped before becoming pregnant are ACE inhibitors, for example Ramipril, Lisinopril etc. Warfarin is another medication your cardiologist may choose to change early in pregnancy (before you are 7 weeks pregnant).

Changing or stopping medicines must be agreed by your cardiologist.

The Obstetrician

The obstetrician is the expert in pregnancy. It is important to see one who has an understanding of the special needs of GUCH women who are pregnant. This often means attending a specialist centre in your region, which is likely to be a teaching hospital. Your cardiologist will also be able to advise which obstetric team has the relevant experience and skills.

The obstetrician will need as much information as possible about your heart. If possible you should have a full report from your cardiologist to take with you.

Both the obstetrician and cardiologist are there to ensure you have a safe pregnancy. However their focus is slightly different. The obstetrician's main focus is the baby and the cardiologist's main focus is your cardiac health. Clearly both you and your baby's health is closely entwined and therefore your cardiologist and obstetrician need to communicate and work closely together to ensure you both do well.

You will need to carefully balance the viewpoints of the cardiologist and obstetrician and be aware they may have differing opinions on how your pregnancy could be managed.

Good general health

This is essential for any woman considering pregnancy. A healthy lifestyle includes having a healthy diet, not smoking, avoiding alcohol and taking exercise.

Pregnancy risks to the woman with heart problems

In some cases doctors may advise you that pregnancy is dangerous and the risk to you is very high.

It might be you are advised that pregnancy should be delayed until further investigations or surgery are performed, or that you should not get pregnant because the risks will always be too great.

Whatever you are advised, you and your partner must make your decision together. The cardiologist is there to advise and counsel you of any risks and the decision you make should take account of the advice and the facts you are given.

Conditions considered High risk in pregnancy

You need to be aware that any woman becoming pregnant faces some risk to their health.

For women without heart problems there is a small risk of dying in pregnancy of around 1 in 20,000. For women with heart disease this risk can range from less than 1 percent to as much as 50 percent (that is 1 in 2 women).

If you have a condition called "*Eisenmenger's syndrome*" or "*Primary pulmonary hypertension*" the risk of death in pregnancy is as high as 50 percent (1 in 2 women).

If you have a condition called "*Dilated cardiomyopathy*" and you have a poor "pump" function of your heart, the risk can range from 10-20 percent.

If you have "*Marfan syndrome*" and the aorta (the large vessel that takes blood from your heart to your body) is enlarged the risk of death or serious complication can be around 20 percent.

If there is *severe narrowing or blockages to the heart valves* e.g. "*Aortic stenosis*" or "*Mitral stenosis*", the risks of death or complications in pregnancy are again high and between 5-10 percent.

If you have one of the above conditions you should not become pregnant until you have been reviewed by a specialist.

Precise estimates of risk are difficult to define and it can sometimes be just that – a risk or chance. Some women considered high risk may survive, and some considered low

risk may suffer a complication and die.

You need to have all the facts about your heart problem and the expected outcome in pregnancy both in terms of your health and the baby's health. You should discuss this with your partner and family and decide what risk is acceptable to you.

The baby's outcome

There is a slightly increased risk of your baby having a congenital heart problem if you have it yourself, around 4-5 percent (one in 20 babies). For women who do not have heart disease the risk of having a baby with CHD is around 1 percent (1 in 100).

Because there is a slightly increased risk that your baby will have a heart problem a detailed echo scan of your baby's heart will be performed when you are around 20 weeks pregnant. Most of the major heart problems can be detected on this scan. If a very serious abnormality is detected, you may be offered the opportunity to terminate the pregnancy and you will need to decide how you feel about this.

The baby's health and outcome is very closely linked to your own health during pregnancy. If your heart's pump is weaker than normal or if your oxygen saturation (the amount of blood that is in your blood) is lower than normal, the developing baby may not get all the nourishment it requires, and it may therefore be small (intrauterine growth restriction) or it may be born prematurely (or 'pre-term' as we now say). With good neonatal care, many small babies can do well after they are born, but some may be left with a permanent handicap.

You need to be aware of the baby's outcome in relation to your specific heart problem and take account of this in addition to your own outcome. Your cardiologist and obstetrician should be able to advise you and help you understand these facts.

The majority of your antenatal care will be done on an 'outpatient' basis. However, if you experience problems or complications you may need admission to hospital to ensure you have enough rest and medical attention. This means that you need to plan for the possibility of spending a lot of time either visiting hospital or staying in hospital during pregnancy if need be.

What happens to you when you are pregnant?

The demand on the heart increases from very early pregnancy. Hormonal changes ensure that the developing baby (foetus) gets plenty of nourishment via the blood flow to the placenta.

You should see your obstetrician as early as possible from about 6-7 weeks and you should also see your cardiologist. They can then make a plan for how often you need to be seen and scanned for example.

At each visit, the obstetrician will check on the baby's growth (by examining your abdomen and feeling and measuring the size of the womb) and your general health.

The cardiologist will ask you if you are experiencing shortness of breath (especially at night) and about your exercise tolerance (asking if you can still climb stairs or walk at your normal pace), palpitations (irregular heart beat) and examine you to check your pulse rate and rhythm, your blood pressure, whether you have any fluid collection at the ankles (oedema) and listen to your chest.

What about the birth?

A vaginal delivery (or natural birth) is safe for the majority of women with heart problems. To reduce the demands on the heart, good pain relief is desirable and sometimes for some heart conditions an epidural is recommended.

Pushing the baby out at the end of labour can be exhausting, and it is sometimes recommended that this part is assisted by the doctors (using either a suction cup or forceps on the baby's head), so it does not take as long.

Caesarean section may be advised for obstetric reasons (the same reasons as in other pregnant women).

When can I go home?

Women with CHD usually need to stay in hospital for longer than average to ensure that the heart adapts to the changes in the amount of blood and fluid in your circulation, which occurs after the baby is born. It can take a few weeks for your circulation to return to the levels before pregnancy, but your longer stay in hospital will allow your cardiologist to review you and make sure you are monitored during the period of highest change.

Blood clots (thrombosis) in the veins of the leg are more

common after childbirth, especially in GUCH women and you will probably be given injections to thin the blood slightly (heparin) until you are fully mobile.

> Thinking of Motherhood

Planning ahead

A would-be GUCH mother needs to ask for specific advice from her own cardiologist before embarking on pregnancy, such as the best timing for becoming pregnant. It is essential to get the full facts about your own particular heart condition and how pregnancy might affect you. If necessary ask your GP to make your concerns known to the hospital, and arrange a clinic appointment even if your usual appointment is not due.

Go to the clinic with a written list of questions:

- What are the risks of the foetus/baby inheriting a similar congenital heart defect?
- What are the risks to i) the mother, ii) the baby
- Should any of your drugs be stopped before becoming pregnant?
- What type of pregnancy and delivery am I likely to have?
- What is the co-operation between the cardiac and obstetric department?

Eat a good balanced diet (including folic acid) and try to improve your general fitness.

Pregnancy

Inform your GP and cardiac department as soon as you know you are pregnant.

Early pregnancy sickness can be very tiring and could also affect how your medications are absorbed in your blood. Seek immediate advice from your GP and rest more, using well-tried non-medical tricks like eating ginger biscuits and bananas and avoiding coffee.

A well balanced diet is critical for the health of you and your baby. Eat plenty of fresh fruit, vegetables, protein, pasta and dairy foods. You should avoid shellfish, soft-cooked eggs and soft-cheeses. Most pregnant mothers put on about two stones in weight. GUCH mothers need to keep an extra check

on their weight gain to avoid unnecessary strain on their heart condition. Try not to eat much chocolate!

Dental care is always important for a GUCH – and it's free when you are pregnant and for one year after the birth of your baby.

Resting in the afternoon really helps to spread out your stamina through the day. It is very difficult with a second pregnancy because of the care needs of the first child. Going to bed early will also help keep you going, even if you need to get up to go to the toilet more often.

Sometimes, GUCH mothers need extra bed rest towards the end of pregnancy, or even an early planned delivery. To avoid running out of time, shop early for your baby supplies (basics such as pram, bath, clothes) when you are less heavily pregnant and less tired.

You could start building up non-perishable goods like tinned food, rice, pasta, cereals, tea, coffee, washing powder – so that when things get hectic after the baby's birth, you will have less to think about!

When buying nappies, baby wipes, nappy sacks, cotton wool etc – buy two packs of everything and two cheap plastic baskets. Keep one basket upstairs and one downstairs and keep them stocked up. This saves you going up and down stairs, especially carrying the baby!

Prams and pushchairs vary enormously in weight – most big manufacturers have a sales brochure with details of the different weights for you to compare. Write to the company or ring a local stockist for details. A three positioned padded buggy can be used from birth to three years and would be lighter than a pram to push.

Delivery

Every birth is different. Make your feelings/worries very clear and then listen to the professional advice you receive. Ask questions about what delivery might be like:

- How long might I be in hospital before the delivery?
- If I would like to, is there any reason why I can not have a normal delivery?
- If a caesarean section is recommended, why is it necessary?
- What type of medical involvement will be necessary?
- If an epidural anaesthetic is advisable to reduce the

stress of pain in labour, will there be a senior and experienced anaesthetist able to give the anaesthetic to someone with a heart problem?

- What are the recommendations to help me deliver the baby when I need to push in the second stage of labour, without becoming too tired?
- Will there be a senior obstetrician available to deliver my baby by forceps/ventouse if required?
- If I need a needle and line put in to my vein, how many will I have?
- Will I be able to hold my baby after delivery?
- What sort of pain relief is advised for someone who has my heart condition?
- Can I see the room where I will have my baby?

Early Days – caring for your baby

All mothers, GUCHs or not, feel exhausted after having a baby – it's very exciting, but very tiring too!

Breast-feeding

- Check that any tablets you take will not affect your baby through your milk.
- Breast-feeding is excellent for your baby, but you need to balance that against your own particular health needs.
- You do not have to shop for milk; you just sit and do it!
- Breast-feeding falls entirely on you as mother, and can be very tiring for a GUCH.
- Your midwife will be able to show you how.

Bottle-feeding

- Buy milk in extra quantities and sterilising supplies. If you run out of these on a day when you feel tired, there is less panic if you have some in reserve.
- Bottle-feeding can be shared by the new father and you might get an odd night's sleep!

Baby clinic

It is essential for your baby to have basic health checks and vaccinations (immunisations). Going to clinic can be a nice trip or a huge hurdle, depending on your energy levels. If you can not get to clinic, contact your health visitor and explain you are a GUCH. She will arrange to visit you at home, or give you telephone advice.

Do not worry about "taking the baby for a walk" unless you

want to and feel like it. Pushing a pram can be very tiring. Sit outside with the baby in good weather, well-wrapped, and have a nice cup of tea!

Caring for yourself

It is NOT fussing to keep a careful eye on your health after giving birth – even if it feels like it. Possible problems like having low iron levels in your blood (anaemia) or common infections could be serious for your heart condition.

If you don't feel well (you have raised temperature, chest pains, dizziness, leg pain) TELEPHONE YOUR GP and ask for a home visit that day.

Make sure you have a good supply of your usual tablets; ring your GP if you get a sore throat or cough to see if you need antibiotics after you have been examined.

You will need a cardiac check-up after the birth to check that your heart (which can get bigger during pregnancy) is returning to its condition before you were pregnant. It is sensible and can be reassuring, as it is very difficult to assess your own tiredness with all the extra physical work that you are doing.

You can ask to see a cardiac social worker at your home if you wish, to discuss the possibility of extra help or benefits.

Rest when the baby does. Keep tiny babies downstairs in a Moses basket or carrycot when they sleep and put your feet up on the settee.

Good hydration is crucial when breast-feeding – make sure that you have plenty to drink during the day, but avoid alcohol. Do the bare minimum of housework – it'll keep.

In order to ensure that you are well nourished (particularly important if you are breast feeding), it is helpful to have food that has been prepared earlier, such as casseroles or sandwiches made the night before.

Play soothing CD's to calm you and the baby down when things are getting difficult!

Accept/ask for help from your partner/friends and family – taking things upstairs, heavy chores, keeping baby baskets topped up. For those of you who live in houses or are on more than one floor, check before going upstairs. See if there is anything that needs to go up and do the same upstairs before you come down. It becomes second nature in time.

As time goes by and your baby grows up

Babies soon learn to roll, crawl and toddle about. They get heavier to lift and they move faster – as their energy levels increase, your energy levels may remain the same or even decrease.

Use a stair gate for safety and peace of mind. Use a second stair gate downstairs to seal off a room and reduce exploring! Playpens are useful if you start using them early and persevere. Consider having a telephone upstairs as well as downstairs.

Buy paper/chubby crayons/glue and simple books. If you need to sit down a lot, why not teach your child to read or acquire pre-reading skills.

If you want to rest, it might be helpful to either watch a programme of your choice or listen to your favourite radio programme with your feet up, cuddling your child and armed with a bowl of raisins!

Toddler Groups are great for meeting other mums with children the same age.

Nurseries – consider the journey there and back and weigh up the advantages. They can give you a much deserved break.

Conclusion

A GUCH Mother deserves to enjoy motherhood because of the extra effort needed to even be a Mother. As we all know, it is hard work bringing up a child and every child's needs are different. Advice can only be given on the likely impact of the task of child rearing on a GUCH's constitution, rather than on how to bring up a child. This is for you to decide along with other Health Professionals, such as your health visitor who is responsible for monitoring your baby's welfare (after the midwife has discharged you when your baby is 10 days old) for the first 5 years of its life.

Enjoy what can be a supremely rewarding experience!



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