



CONGENITAL HEART DISEASE ADULTS SEXUAL HEALTH & PREGNANCY



This fact sheet provides general information and will help you ask questions of the doctors looking after you.

My congenital heart disease (CHD) diagnosis, sex and pregnancy – the facts!

When you have congenital heart disease, there are a few things to be aware of as you consider commencing a sexual relationship:

- The majority of congenital heart diseases do not reduce fertility. You need to think about contraception, and discuss that with your doctor just like every other young person
- No congenital heart disease protects you from sexually transmitted infections (STI's). You need to think about condoms, to reduce your risk of an STI, just like every other young person. Your GP is a great resource for any questions!
- If you are a young woman with congenital heart disease, then the discussion regarding contraception may start with your GP but should involve your cardiologist. You may be sent to another specialist (e.g. a gynecologist) for further conversations.
- Whether you are a young woman or a young man with congenital heart disease, then your chance of having a baby with a condition is increased. For most congenital heart diseases, the increase is small (overall around a 4 – 7% chance) BUT the risk is higher if:
 - Your congenital heart disease is just one of several issues with your health, physical or mental development
 - Other members of your family also have congenital heart disease
 - Your congenital heart disease is part of a known genetic syndrome. The commonest genetic syndrome seen in CHD is 22q11 deletion. If this is shown to be the case in you, then every child you have has a 50% risk of inheriting this genetic change. This is expressed as a syndrome, with congenital heart disease being just one aspect .
- Most congenital heart disease does not get inherited in exactly the same way between relatives – because the genetic component for most is just a small contributor. Although the chance of having a baby with congenital heart disease is small for most adults with congenital heart disease, babies who are born with a CHD diagnosis may have a different diagnosis to that of their affected parent.
- Many women with congenital heart disease can safely have a baby, but in a small number pregnancy may be associated with significant risks. In some women, pregnancy may be contraindicated if considered too high risk. If you are a young woman with congenital heart disease, then a planned pregnancy is really important. This is because you and your cardiologist will want to make sure that you are in the best state to cope with the physical demand pregnancy puts on your heart. There may be changes in medications (some are contraindicated in pregnancy), interventions or operations that are advised first.



- Many adult congenital heart disease services work with an obstetric service. Women with congenital heart disease may be advised to deliver at an obstetric hospital that is not their local obstetric hospital. Sometimes, a team of doctors, nurses, midwives, neonatologists (baby doctors), anaesthetist's and other specialist doctors are required. Sometimes the congenital heart disease or complications in pregnancy mean that a baby will need to be delivered early. It is more common to have a caesarean section when there are concerns about the health of the mother or the baby.

When should I have sex?

Only you can decide when is the right time to start a sexual relationship. Most young people find talking to friends or family helpful. Don't be embarrassed to ask questions – it's always good to get your facts straight. Starting a sexual relationship is not just about being ready to deal with the consequences discussed above – it is most importantly about your emotional wellbeing, so make sure that it is what you want! From the physical point of view, having sex is reasonably strenuous, and as a guide requires a similar amount of effort as that required to climb approximately 2 flights of stairs.

Preventing pregnancies and STI's

Contraception is used to reduce the chance of pregnancy. This is sometimes also referred to as birth control. There are many different ways to reduce the chance of becoming unexpectedly pregnant. All young people should consider a discussion with their GP and cardiologist about the options, their effectiveness and possible side effects. Only condoms, which provide a physical barrier, can reduce the risk of STI's. However, their contraceptive rating is not as high as other options and therefore many people use 'contraception plus a condom'. Many of the contraceptive options will suit women with congenital heart disease. However, you should discuss this first with your cardiologist.

The oestrogen containing pill does increase the risk of blood clots, and so for some women this type of contraception is not recommended. The best thing to do is have a chat with your doctors about the options to help you decide which is best for you. This is a process that some young people find tricky, regardless of whether they have a heart condition or not! Make sure that you are comfortable with the information you have and decision you make. It is an important one and may be one of the first health related decisions you make for yourself.

Emergency contraception is available. Examples of when you may need this include:

- reduce the chance of pregnancy after unprotected sex,
- contraception failure (e.g. condom breakage)
- concern about contraceptive failure (e.g. vomiting/diarrhoea whilst on the pill)

Emergency contraception can be purchased over the counter (without a script) in Australia. It is a good idea to see your GP regarding any concern about exposure to an STI. Always ask your pharmacist (when purchasing any over the counter or prescribed medicines) about any interactions that may reduce the efficacy of your contraception, as well as other possible interactions that might affect how well any of your medications work.

Sexual health issues in men

There is very little data on fertility in men with congenital heart disease. However, fertility can be reduced with chronic ill health in both men and women. Some heart medications may cause erectile dysfunction or impotence (which means difficulty with getting and maintaining an erection). It is really important that you chat to your cardiologist if this is an issue to find out whether any of your medications may be responsible, and explore what other options are available.

Can women with congenital heart disease have children?

For most women the answer is yes. Some complex types of congenital heart disease are associated with a significant risk to the mum. A risk to the mum will always increase the risk to the baby:

- mainly an increased risk of miscarriage,
- early delivery
- having a very small baby.

In a smaller number of women with congenital heart disease, pregnancy will be extremely high risk. Sometimes that risk can be reduced. For example, in some women a valve replacement, followed by some months to allow heart recovery before conception, may be advised.

To have the best chance of a safe, successful pregnancy and a healthy baby, have a chat to your cardiologist – even before you start thinking about having a baby!

It is good to know what tests will need to be undertaken and, if an intervention might be required, an approximate time frame. It is important to know whether any medications you are on would need to be stopped. You may need to have a plan for changing medications. Sometimes, your cardiologist will want to involve other medical specialists in the assessment before advising you about what risks pregnancy might have for you. It is really good for you to have an understanding about these issues, so that you can take charge of your health and plan your life. In some women, pregnancy will be considered too high risk.

I'm pregnant – and I don't know what to do

You can access counseling to help you make your decision about an unplanned pregnancy - seek out family planning services in your area. You can also chat to your GP and your cardiologist. Legislation around pregnancy termination (abortion) varies in Australia from state to state. Very early in pregnancy, medication may be able to be used to cause a miscarriage; otherwise a surgical procedure is required.

What about delivery?

Most women with congenital heart disease can have a vaginal delivery. However, pregnancy and delivery is difficult to predict – and unexpected medical or obstetric issues can develop. Sometimes, plans for delivery need to be changed, including during delivery itself if an emergency arises. Your cardiologist and obstetrician/ obstetric service will communicate during your pregnancy to plan together with you. During pregnancy, you (or your partner, if you are a Dad with congenital heart disease) will be referred for a detailed ultrasound of the baby's heart in addition to the usual scan.

Post partum (after giving birth) and beyond

Depending on your diagnosis, you may spend more time in hospital, have more tests or more complications after delivery than women without congenital heart disease. Depending on your type of heart problem and your pregnancy, your baby may be small for their age. If babies are born very early or are small, they may need to go to a neonatal intensive care unit or special care nursery.

There are some changes that occur in women's hearts during pregnancy. These usually resolve over a few weeks to months. Sometimes however, pregnancy can cause heart function to reduce, and so you should always have a discussion and assessment with your cardiologist before deciding to get pregnant again.

It is important to consider whether you should commence contraception before going home from hospital. What you use may depend on your decision regarding breast feeding and/or your anticipated subsequent pregnancy plans

Where can I go for further help?

People with congenital heart disease face unique challenges, treatment and often repeated surgeries for their entire lives, and support is critical at every stage of the journey – from when congenital heart disease is diagnosed through childhood, the teenage years and into adulthood.

HeartKids is the only national charity dedicated to supporting Australians of all ages impacted by congenital heart disease, the leading cause of infant death in Australia and a complex chronic disease requiring lifelong treatment.

For over forty years, HeartKids has provided timely support to infants, young people and adults living with congenital heart disease all across Australia. We also fund life-saving research, provide reliable and evidence-based information and advocate for the needs of impacted families.

Our support is a commitment for life.



HeartKids would like to acknowledge our guest author - with thanks.
A/Prof Dominica Zentner, Cardiologist, Royal Melbourne Hospital.

References for further reading

Australian sites – counselling and abortion

- Pregnancy Counseling Australia** (24 h hotline) 1300 RESPECT
- Abortion services in your state can be found via **Family Planning Australia**
<http://familyplanningallianceaustralia.org.au/services/>
- Information is available on the above sites on contraception, however this is not specific for individuals with congenital heart disease.

Overseas sites – information for people with a heart condition

- CHDs impact on females** (American Heart Association)
http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/TheImpactofCongenitalHeartDefects/CHDs-Impact-on-Females_UCM_307113_Article.jsp#.W11YSi1L2jQ
- Contraception for Women with a Heart Condition** (Somerville Foundation, UK)
http://www.thesf.org.uk/documents/flyers/TSF_Contraception-for-Women-with-a-Heart-Condition_web.pdf#search='contraception'
- GUCH** (Grown up congenital heart disease) and **Pregnancy** (Somerville Foundation, UK)
http://www.thesf.org.uk/documents/flyers/TSF_Pregnancy_DL_web.pdf
- Pregnancy, living with a heart condition** (British Heart Foundation)
<https://www.bhf.org.uk/information-support/support/practical-support/pregnancy-with-a-heart-condition>

Actelion has supported the development of this factsheet for educational purposes, with no influence on the clinical content.



All HeartKids Ltd information is endorsed by our Clinical Advisory Committee.
HeartKids information does not replace professional medical advice.
People should ask their doctor any questions about diagnosis and treatment.
HeartKids 2018.

