



CONGENITAL HEART DISEASE DIAGNOSIS

When you first learn that your baby has a heart condition this can cause a range of emotions and leave you feeling overwhelmed. This is a normal reaction but remember that you are not alone. Congenital heart disease (CHD) is common, and there is great variability in its severity. There is good treatment available for most forms of CHD, and rapid advances are occurring in treating the condition all of the time.

In many cases, congenital heart disease will be diagnosed before a baby is born, during an ultrasound scan in pregnancy. Often CHD is first detected soon after birth, and for some not until later in childhood. Whenever the diagnosis is made this can have a profound impact on your life and on the life of your family.

There are many advances in medical research and technology that have increased knowledge, skills and understanding of congenital/childhood heart disease. Despite this fact, in most cases the causes of congenital/childhood heart disease are still unknown.



You are not alone.

When you hear that your child has a heart defect, it is easy to feel isolated, shocked and alone. However, research shows that congenital heart defects are among the most common types of birth defect, affecting about 1 in 100 babies. In Australia, 8 babies are born each day with some form of congenital heart defect.

Some babies and children with CHD require no treatment at all, while others may require regular medication or surgery. The best course of treatment will be decided by the treating team, and decisions are always made on an individual basis.

Understanding that there are others who are going through similar experiences to you and your family often helps but does not always reduce the feelings of grief, loss or shock experienced upon receiving the news of your child's heart condition.

This factsheet is aimed at helping you understand some facts about CHD and aims to give you resources on how to obtain more support if you need.

Congenital heart defects

A congenital heart defect is a structural abnormality of the heart that you are born with. This can lead to a range of effects to do with how the heart functions, for example a chamber of the heart or a blood vessel may be under-sized, a valve may be narrowed or leaky, or there may be a type of hole between

Initial reactions and coping

Hearing that your child has a heart condition can be very upsetting for parents, carers and for each member of the family. It is natural to experience feelings such as shock, denial, anger, sadness and detachment. Some people will experience these feelings more intensely than others and take a longer time to adjust.

Sometimes, parents feel guilty and think that they are to blame for their child’s heart problem. Usually, there isn’t a clear reason why a child has a heart problem, although it is perfectly normal to want to know why.

Everyone has different coping strategies, and it is important to find what works best for you. Whichever option and pathway of care you choose, there is support available for you and your family.

HeartKids has a Support Team for those who are living with the realities of congenital heart disease. Part of their role is to provide support and help develop coping strategies for those impacted by congenital heart disease. HeartKids offers in-hospital support for families and has programs in the community for families to connect with others who have been through something similar.

If you would like more information or assistance, please contact HeartKids Helpline on 1800 432 785 or visit heartkids.org.au for more information.

Tips to help with your cardiologist appointment	Some questions to ask.
<p>Take a family member or friend with you for support.</p> <p>If you would like further support ask the medical team for information on how to connect with the Social Work Team in the hospital.</p> <p>Plan what you would like to ask before your visit but don’t hesitate to ask new questions during your visit or ask for clarification.</p> <p>Write your questions down, to help you remember them when you are with the health professionals.</p> <p>Feel free to take notes or write important information down if that helps you remember what was discussed.</p> <p>You may ask the medical professionals if they have a diagram or factsheets for you to take home.</p>	<p>What is the name of my child’s heart condition?</p> <p>What will happen when my baby is born?</p> <p>Will my child need surgery?</p> <p>What extra precautions do I need to take while pregnant?</p> <p>You should expect your doctor (paediatric cardiologist) to explain:</p> <ul style="list-style-type: none"> The precise nature of the heart condition The treatment that may be needed The long-term outlook or prognosis <p>Before you leave an appointment with a healthcare professional consider:</p> <ul style="list-style-type: none"> Writing down the names and contact details of those you have seen and the best way to reach them. Writing down the name of the heart condition and other useful information. Asking the doctor or nurse specialist to draw a diagram to help with the explanation.

Where can I go for further help?

People with congenital/childhood 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/childhood 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.



References for further reading

- Davies, L & Mann M. 2013. **Heart Children: A practical handbook for parents of children with congenital heart conditions.** Auckland: @Heart Inc.
- Heart Centre for Children. 2017. **Congenital/childhood heart disease** (Online). The Children's Hospital at Westmead. Available: <http://www.heartcentreforchildren.com.au/childhood-heart-disease.html>
- Leggat, S. 2011. **Congenital/childhood heart disease in Australia: Current practices and future needs.** Pennant Hills, NSW: HeartKids Australia.



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.

