



HeartKids

Navigating a new diagnosis

A guide for recently diagnosed adults and young people.

Receiving a Congenital Heart Disease (CHD) diagnosis can be challenging. It's a lot to take in, but it's important to know you're not alone in this journey. Many people are living with congenital heart conditions in Australia. Here's some information to help you understand your new diagnosis.

Understanding your diagnosis

To best understand what your diagnosis means for you, take as much time as you need to review the information provided to you by your healthcare team, including treatment options, and potential outcomes specific to your situation. Ask questions and bring up any concerns you have. You may want to take notes and keep a running list of questions to ask each time you see your doctor.



Outlook and treatments

Although there is no universal cure for CHD, the landscape of treatment options, including surgical interventions, continue to advance. Many young individuals with heart conditions successfully lead long and healthy lives. While some may not require any treatment, others might need regular medication or undergo multiple surgeries. Your medical team will customise a treatment plan based on your unique situation.

Each person's journey with CHD is unique, and your healthcare team is dedicated to making decisions tailored to your individual needs. Approach your treatment one step at a time and know you're not alone on this journey!

Thanks to medical advancements over the last six decades, adults now outnumber children living with Congenital Heart Disease (CHD) in Australia, highlighting the significant progress in long-term health outcomes for those impacted.



How did my heart condition occur?

This is a common question, and while it is normal to seek understanding about how your heart condition developed, in most cases of CHD, the cause remains unknown.

Congenital heart defects are among the most common types of birth defects, affecting 1 in 100 people. In Australia, approximately 8 babies are born each day with some form of CHD.

Researchers and advocates, like HeartKids, are working hard to learn more about CHD through ongoing research, and awareness campaigns to improve understanding and care for people with CHD.

Common feelings

A new diagnosis can have a profound impact on your life. It is natural to experience feelings such as shock, denial, anger and sadness. Some people will experience these feelings more intensely, or may take longer to adjust than others.

It's important to recognise and acknowledge these feelings, and if you can, work through them with a mental health professional or counsellor.

HeartKids can help you navigate your journey at your own pace.

IN **8 OUT OF 10**
CASES OF CONGENITAL
HEART DISEASE

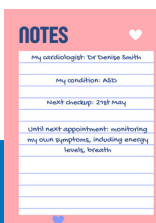


THERE IS **NO KNOWN CAUSE**²

Preparing for cardiology appointments

At a cardiac appointment, your doctor or cardiologist will perform physical examinations, and order tests like electrocardiograms (ECGs or EKGs) and echocardiograms to assess your heart health. This is the time to discuss your symptoms, raise any concerns, and create a tailored treatment plan or receive guidance on lifestyle changes. Regular attendance at these appointments is important for actively monitoring and managing your heart health. To get the most out of these appointments you can:

- **Take a family member or friend.** They can offer you support at the appointment.
- **Write down and bring questions with you.** It's easy to forget your concerns or questions once you're in the appointment.
- **Take notes and ask for information to take home.** Write important information down so that you can remember what was discussed. You should also write down the names and contact details of the health professionals you spoke to.



Useful questions to ask at appointments:

- What is the name of my heart condition? How does it impact the normal workings of my heart?
- What treatments will I need? Will I need surgery?
- Is there anything I have to be careful with, for example exercise?
- What is my long-term outlook or prognosis?

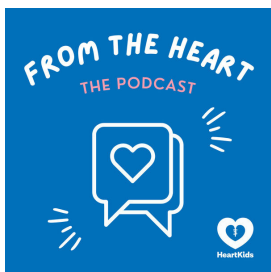
Preparing for surgery

Facing heart surgery can be overwhelming, but there are practical steps you can take to prepare mentally and physically. Acknowledging the emotional aspect is important as the physical impact that will occur. To prepare mentally and physically, ensure that you:

1. Learn about your procedure and potential outcomes.
2. Get your support network of family and friends ready to provide emotional support for your recovery period.
3. Consider practicing relaxation techniques, such as deep breathing or meditation, to help manage anxiety.
4. Follow the pre-surgery guidelines provided by your medical team to help make your recovery as smooth as possible.

Connecting with others with CoHD

Connecting with others who've faced childhood heart disease is a great way to feel supported. Consider joining one of HeartKids support or social media groups to learn about other people's experiences and gain deeper understanding into how to navigate your own journey.



HeartKids also has a podcast called "From the Heart" which is available via the HeartKids website and most streaming platforms.

Listen to "From the Heart" and hear stories from adults, teenagers and families navigating their CoHD journey. The podcast regularly features healthcare professionals and other experts who offer valuable advice on how to live your best, healthiest life with a childhood heart condition.

Where to find more information and support

HeartKids

 heartkids.org.au

Learn more about CHD and the support HeartKids can offer you.

 1800 432 785

Call the HeartKids Helpline for support, advice and guidance.

 @HeartKidsAustralia

 @HeartKids

References

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This fact sheet was reviewed and updated by HeartKids in February 2024. It was endorsed by our Clinical Advisory Committee at the time of publication. Clinical information might change after this date. The information in this fact sheet is general. It is not a substitute for medical advice from your doctor. Always talk to your doctor about matters that affect your health.