



# Navigating a new diagnosis

Information for parents or carers who have recently received a new diagnosis for their child.

**Learning for the first time that your child has a heart condition can cause a range of emotions.**

It can leave you feeling overwhelmed. It is important to remember you are not alone. Childhood heart disease (CHD) is common, and the severity of each case varies. These days, there are good treatment options available for most forms of CHD.

## How is childhood heart disease diagnosed?

Many cases of congenital heart disease are diagnosed before a baby is born, during an ultrasound scan in pregnancy. Other cases are first detected soon after birth. Some cases of congenital disease are not diagnosed until later in childhood or in rarer cases, in adulthood.

Cases of acquired heart disease can develop in childhood due to an illness or infection.

## What is the outlook?

There is no cure for CHD, but treatment options are improving all the time. Most children with heart problems go on to live long and normal lives.

Some babies and children with CHD need no treatment at all. Some cases are more complex and may need regular medication or many surgeries. Your medical team determines the outlook and best course of treatment. Their decisions are always made on an individual basis.



Today there are more adults than children living with CHD in Australia. This is due to rapid medical advancements over the past 60 years.

## Common feelings

A new diagnosis can have a profound impact on your life and on the life of your family. Hearing that your child has a heart condition can be very upsetting.

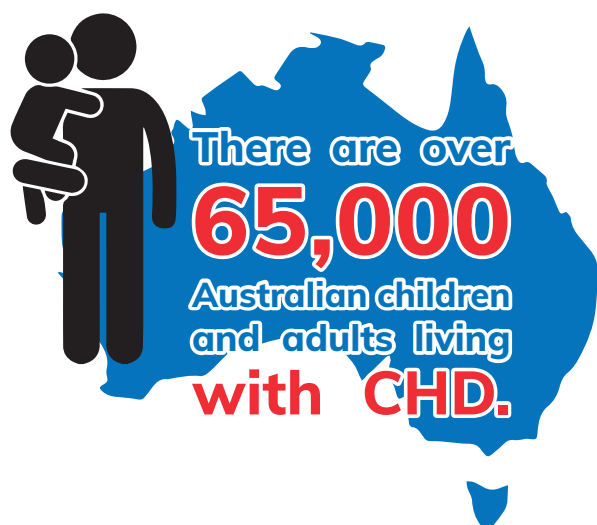
It is natural to experience feelings such as shock, denial, anger, sadness and detachment. Some people will experience these feelings more intensely, and some people may take longer to adjust than others.

Every family's journey of CHD is unique. HeartKids can help you navigate your journey at your own pace.

## Why did this happen to us?

This is a common question. When you are told that your child has a heart defect, it is easy to feel shocked and isolated. It is important to remember you are not alone.

Congenital heart defects are among the most common types of birth defect, affecting 1 in 100 babies. In Australia, that means around 8 babies are born each day with some form of congenital heart defect.<sup>iii</sup>



Sometimes parents might feel guilty or think they are to blame for their child's heart condition. Although it is normal to want to know why this has happened, in most cases of congenital heart disease, the cause is unknown.

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



THERE IS **NO KNOWN CAUSE**<sup>2</sup>

## Preparing for your first cardiology appointment

### Tips:

- **Take a family member or friend.** They can offer you support at the appointment.
- **Connect with the social work team.** Ask the hospital how to connect with their team of social workers for extra support.
- **Spend some time thinking about what you want to ask.** Write your questions down so that you can remember them during the appointment.
- **Take notes.** 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.
- **Ask for information to take home.** There may be diagrams or fact sheets you can take home for extra information.

### Ideas of questions to ask:

- What is the name of my child's heart condition? How does the condition impact the normal workings of their heart?
- Do I need to take any extra precautions while pregnant?
- What will happen when my baby is born?
- What treatment will my child need? Will my child need surgery?
- What is the long-term outlook or prognosis?

## 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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<sup>ii</sup> KHAIRY, P., IONESCU-ITTU, R., MACKIE, A. S., ABRAHAMOWICZ, M., PILOTE, L. & MARELLI, A. (2010). "Changing mortality in congenital heart disease." *Journal of the American College of Cardiology*. 56: 1149- 1157.

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<sup>v</sup> BLUE, G. M., KIRK, E. P., SHOLLER, G. P., HARVEY, R. P. & WINLAW, D. S. (2012). "Winlaw DS. Congenital heart disease: current knowledge about causes and inheritance." *The Medical Journal of Australia* 197: 155- 159.

This fact sheet was reviewed and updated by HeartKids in March 2021. 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.