



HeartKids

LEARNING OF A NEW DIAGNOSIS

Information for Aboriginal and Torres Strait Islander families who have a child with a heart condition.



Finding out your child has a heart condition

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

It is important to remember you are not alone. There is lots of support available.

8 BABIES

ARE BORN WITH A
HEART CONDITION



EACH DAY
IN AUSTRALIA.¹

What will happen?

There is no cure, but there are good treatments available for most types of childhood heart disease (CHD), including for rheumatic heart disease (RHD).

The doctors will explain what treatments your child could need. They are experts at treating heart problems in children.

If you don't understand something, you can ask them questions.

It was complete shock at first. I didn't understand what was happening to my son, so it was scary. As soon as you can get your questions answered, you start to feel calmer.

— Mandela, Yawuru woman

Tips from other families

Ask questions.

It added to my stress when I didn't know what was going on. You can ask the doctor to slow it down or to draw a picture.



Ask for help.

Don't be shy or shame. If you don't feel comfortable asking the doctors, ask someone you feel safe speaking with.



Use support services.

That might be HeartKids, the social work team at the hospital and Indigenous liaison team.



Look after yourself.

There are women's groups and men's groups for support. As parents, we need to look after ourselves too.



Connect with others.

When you speak to another parent or family who knows what you are going through, it makes the conversation easier.



Take family or a friend.

They can offer extra support at the hospital or at appointments.



Questions to ask at the first appointment

- What is the name of my child's heart condition?
- How does the condition change the normal way the heart works?
- Will my child need surgery or treatment?

Where to find more information and support


HeartKids

 heartkids.org.au

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

Helpline services

 Call: 1800 432 785

 SMS: 0427 895 785

 Webchat: heartkids.org.au

Contact the HeartKids Helpline for support and information.

Follow us on social media

 @HeartKidsAustralia

 @HeartKids

References

1. VAN DER LINDE, D., KONINGS, E., SLAGER, M., WITSENBURG, M., HELBING, W., TAKKENBERG, and J. J. & ROOS-HESELINK (2011). "Birth prevalence of congenital heart disease world-wide: a systematic review and meta-analysis." *Journal of the American College of Cardiology*. 58: 2241-2247.
2. CELERMAJER D, STRANGE G, CORDINA R, et al. Congenital heart disease requires a lifetime continuum of care: A call for a regional registry. *Heart Lung Circ*. 2016;25(8):750-754. doi:10.1016/j.hlc.2016.03.018

This fact sheet was reviewed and updated by HeartKids in July 2022. 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.