

**HeartKids**

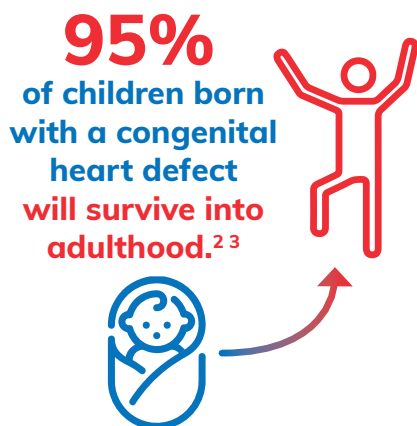


# Adulthood with your heart condition

Information for adults on how to stay healthy and up to date with their care.

## How many adults are there with CHD?

Each day, eight babies are born with a heart defect in Australia.<sup>1</sup> The past 60 years have brought dramatic surgical and medical advances, and increased life expectancies.



There are over 65,000 Australians currently living with CHD.

About half of these people are adults, and this number is increasing by 5% each year.<sup>4</sup>

## Why is CHD unique?

There are many different types of childhood heart disease (CHD). The care and treatment needs of each person are unique. These needs are also different to those of adults with other heart problems.

CHD is a life-long condition. It poses different challenges for adults than it does for children. Most people with CHD will need regular check-ups with a specialised cardiologist for their entire lives.

## What is transition?

Transition is the process of learning about how to manage your life and health care more independently. The transfer of care from paediatric to adult health services occurs around the time you are 18 years old. Some hospitals run programs to prepare young people for transition. These programs are relatively new. If you have already transitioned to, you may not have had access to a transition program.

## Why is it important to stay on top of my health care?

Adults with CHD can lead full and active lives with the right care and management.

Most people with CHD need long-term monitoring. You may have had a defect repaired during childhood but over time you may need more repairs. Or sometimes new issues can arise.

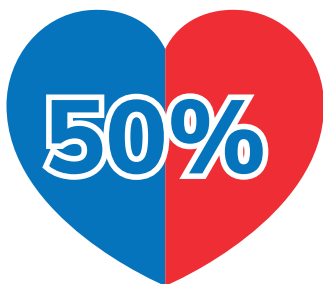


Even if you didn't need surgery or treatment when you were younger, it is important that adults with CHD continue to have regular check-ups.

Regular check-ups allow your doctors to identify any issues with your heart before they cause larger problems.

You may be at an increased risk of complications if you do not get follow-up care. This can include arrhythmias, reduced exercise capacity, late heart failure, or even death.

Some studies  
*estimate* that up to



of people with CHD are  
**failing to follow-up** their  
care after transitioning  
to adult services.<sup>5 6</sup>

### Tips to stay on top of your care:

- **Learn about your condition.** Understanding your condition will enable you to monitor it better and know when to contact your cardiologist to report changes.
- **Keep a copy of your medical history.** Having a record of your surgeries and treatments helps you to manage your condition.
- **Attend regular check-ups.** Seeing your doctor regularly allows you to make sure you are staying healthy.

## Making healthy choices

As adults, we make lots of life and lifestyle choices. It is important to understand the possible impacts on your heart condition.

Issues to consider include:

- **Exercise.** How can I exercise in a safe way?
- **Employment.** Are there any limitations for me due to my heart condition?
- **Pregnancy and family planning.** Are there any risks for me or my family?
- **Alcohol, smoking and drugs.** What are the extra risks?
- **General cardiovascular health.** What is a healthy weight, cholesterol level and blood pressure?
- **Mental health.** Being comfortable talking to your doctor about your mental health is also important.

Open communication with your doctor can help you to navigate these choices. They can help you determine what the risks of certain lifestyle choices are for you, and how to reduce any harm to your health and wellbeing.

If you have all the information, you will be able to make the most informed choices for your health.

## Preparing for appointments

Attending your follow-up appointments allows you to make sure you are staying healthy.

If possible, try to see a cardiologist who specialises in adult congenital or childhood-acquired heart care.

### Tips for your appointment:

- **Take a family member or friend.** They can offer support at the appointment.
- **Spend some time planning.** Write down the questions you would like to ask so that you can remember them during the appointment.
- **Take notes.** Write important information down so that you can remember the details. This includes the names and contact details of the health professionals you speak to.
- **Ask for information to take home.** They may have diagrams, fact sheets or useful websites you can read at home for extra information.

### Ideas of questions to ask:

- What's the most likely cause of my symptoms?
- What tests do I need?
- What treatments are available? Which do you recommend for me?
- How often should I get screened for complications?
- I have other health conditions. How can I best manage these together?

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.

## References

- <sup>1</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.
- <sup>2</sup> LE GLOAN, L., MERCIER, L., DORE, A., MARCOTTE, F., IBRAHIM, R., MONGEON, F., ASGAR, A., MIRO, J., POIRIER, N. & KHAIRY, P. (2011). "Recent advances in adult congenital heart disease." *Circulation*. 75: 2287- 2295.
- <sup>3</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.
- <sup>4</sup> CELERMAJER, D., STRANGE, G., CORDINA, R., SELBIE, L., SHOLLER, G., WINLAW, D., ALPHONSO, N., JUSTO, R., NICHOLAE, M., KASPARIAN, N., WEINTRAUB, R. G., CHEUNG, M., GRIGG, L. E., BRIZARD, C. P., WHEATON, G., DISNEY, P., STEWART, S., BULLOCK, A., RAMSAY, J., GENTLES, T. & D'UDEKEM, Y. (2016). "Congenital Heart Disease Requires a Lifetime Continuum of Care: A call for a Regional Registry." *Heart, Lung and Circulation*. 25(8): 750-754.
- <sup>5</sup> CELERMAJER, D., NICHOLAE, M., HORNUNG, T., O'DONNELL, C., JUSTO, R., BULLOCK, A., CHEUNG, M., COCHRANE, A., GENTLES, T., RAMSAY, J., SHOLLER, G. & WHEATON, G. (2013). "Adult Congenital Heart Disease (ACHD) Recommendations for Standards of Care.". from [www.csanz.edu.au](http://www.csanz.edu.au). 86 NICOLAE, M., GENTLES, T., STRANGE, G., TANOUS, D., DISNEY, 6 P., BULLOCK, A., GRIGG, L., CHEN, S.S.M., PRESSLEY, L., CORDINA, R., HORNUNG, T., O'DONNELL, C. & CELERMAJER, D.S. (2019). "Adult Congenital Heart Disease in Australia and New Zealand: A Call for Optimal Care." *Heart, Lung and Circulation*. 28: 521-529.

## Where to find more information and support

### HeartKids

 [heartkids.org.au](http://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.

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### Heart Foundation

 [heartfoundation.org.au](http://heartfoundation.org.au)

The Supporting Young Hearts program connects adults (18 to 45 years) together to share stories and knowledge.