



CONGENITAL HEART DISEASE ADULTS



The rising number of adults with congenital heart disease

Every day, 8 babies are born with a heart defect in Australia. The past 60 years have brought dramatic surgical and medical advances allowing more than 90% of these children to live into adulthood. As medical knowledge and surgeries advance the number of adults with congenital heart disease has increased resulting in more adults living with congenital heart disease than children. It is estimated that 64,000 Australians are currently living with a childhood heart condition. About half of these people are adults, and this is increasing by 5% each year.

Congenital heart disease is unique in each individual case and as such the care and treatment needs of each person are unique as well. Congenital heart disease poses different challenges for adults than it does for children and the majority of people with a congenital heart defect will require regular check-ups with a specialised cardiologist. Congenital heart conditions are different to other common heart conditions such as coronary artery disease.

Congenital heart disease is the most common birth abnormality, affecting 1 in every 100 babies



Transitioning from paediatric to adult care

When a young person reaches the age of 18, their cardiac care will be transferred from a paediatric centre to an adult hospital. The transition process can be a stressful one for the family involved. For more information on Transition and related services please see the ***HeartKids Factsheet on Congenital heart disease in Young People.***

Transition programs are relatively new and there are many people who are currently living with congenital heart disease that may not have accessed support available to them and their family through this process. It is useful to understand the benefits of continuing cardiac appointments. Many people find the new hospital confronting and may decide to no longer attend appointments.

Health concerns

Most people who have a congenital heart disease require long term monitoring of their heart condition and overall health. In childhood, the heart condition may have been repaired, however over time additional repairs may be required or other problems may arise that require investigation and treatment to prevent complications. Therefore, it is important to have regular monitoring of the heart and overall health. Adults with congenital heart disease can lead full and active lives with the right care and management.

It is important that people living with congenital/childhood heart disease have regular check-ups with a cardiologist who works with adults living with congenital heart defects to ensure their care needs are met and that they are living a well-balanced and healthy lifestyle.

It has been found that lack of information and guidance may lead to adults to no longer attend cardiac appointments. This is called “loss to follow up”.

Studies indicate that loss to follow up rates for transition to adult care are over 50%.

Adults who do not receive follow up care for their cardiac condition are at an increased risk for health concerns such as arrhythmias, reduced exercise capacity, late heart failure and even death. Attending appointments with specialists can increase the likelihood of issues being promptly dealt with. Having regular follow up appointments and developing a relationship with a GP ensures that individuals overall health and wellness is the focus and allows the person living with congenital heart disease to more effectively manage their condition.

Treatment and care needs are different to those adults with heart problems such as coronary artery disease.

The health concerns of patients with adult congenital heart disease may be grouped into the following categories:

1. Ongoing check-ups of defects corrected in childhood
2. Ongoing monitoring of a defect diagnosed in childhood that has not required an intervention
3. A new diagnosis of congenital heart disease in adulthood
4. Psychological and mental health concerns
5. Physical limitation, including exercise capacity

Some of the cardiac health concerns that may arise for adults with congenital heart disease include:

1. New rhythm disturbances and/or the need for pacemakers
2. Weakening of the heart muscle function
3. Leaking or narrowing of the heart valves

Most of these issues have effective treatments so see your cardiologist regularly to keep well.

Lifestyle Choices

As adults there are many lifestyle choices that can be made, such as where we live, what jobs we do, if we drink alcohol, relationships and much more. Open communication with a specialist and GP can assist with understanding the impact of lifestyle choices on heart conditions. For example, alcohol consumption, exercise, having children and employment considerations.

Discussing your heart condition, asking questions of your doctor allows you to make informed choices for your own health and safety. It is important that as an adult, no matter your age, to learn as much as you can about your heart condition, medication and required treatment to ensure that you are living the healthiest possible life.

Other important issues to consider for an adult with congenital heart disease include:

1. Pregnancy
2. Questions about exercise and training
3. All the usual adult cardiovascular considerations including weight, cholesterol and high blood pressure

Adults with congenital/childhood heart disease require additional information and support for their unique health concerns relating to their heart condition.

HeartKids encourages all people with congenital heart disease to learn as much as possible about their condition. Understanding your condition and its treatment means that you can respond quickly and know when to contact your cardiologist to report changes or concerns. Obtaining a copy of medical history such as surgeries or other treatments undergone for your own record and knowledge may be useful in helping manage your heart condition.

Tips to help with your appointments:

- Take a family member or friend with you for support.
- Plan what you would like to ask before your visit – but don't hesitate to ask new questions while you are there.
- Write your questions down, to help you remember them when you are with the doctor.

Some questions to ask include:

- What's the most likely cause of my symptoms?
- What tests do I need?
- What treatments are available? Which do you recommend for me?
- What kind of exercise program is best for me? Are there particular activities that are best avoided?
- How often should I be screened for complications from my heart defect?
- What contraception should I use?
- Are there any concerns about me getting pregnant?
- I have other health conditions. How can I best manage these conditions together?
- Are there brochures or other printed material that I can have? What websites do you recommend?

Where can I go for further help?

People with congenital 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 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

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