



CONGENITAL HEART DISEASE YOUNG PEOPLE

Every day in Australia, 8 babies are born with a heart anomaly. Some of these anomalies will be minor and will need no intervention at all. Some may require medicine, and others may require one or more operations. The past 60 years have brought improvements in heart surgery, medical technology and clinical knowledge. This means that overall, more than 90% of children born with a heart condition continue to live through childhood, their teenage years and adulthood.

Here, young people refers to anyone aged between 12-25 years.

Young people with heart disease can live long, full and active lives, but may have unique needs and challenges associated with their condition and its treatment. The transition from paediatric to adult health care services may be one challenge. It can be hard to meet a new health care team and try to navigate your way through a new hospital or health system! Young people with heart disease may also be more likely than their peers to experience a physical or mental health concern. Emotionally, young people who have had a serious medical illness during childhood can experience worries, fears and concerns about their health and future.

HeartKids provides
lifelong support for heart kids
and their families



Adolescent Development

According to the [World Health Organisation](#) (WHO), adolescence is a period in a person's life that has unique challenges. Adolescence is a period when children transition between childhood and becoming an adult. During the adolescent years, young people develop greater knowledge and skills to manage their emotions and relationships, and develop capacities to help them navigate their lives and take on adult roles. Each young person will do this in their own time and their own unique way.

Goals of adolescence are that young people grow to become autonomous adults, reach their educational or vocational goals, and participate in society. Young people with heart disease, like all young people, need to learn how to navigate these changes, and having a health condition can place extra demands, especially during times of change, emerging identity and growing independence.

For a young person with heart disease this means learning to manage your own health. This includes:

- remembering your medications (what they are for and how often to take them),
- learning more about your heart condition and medical history,
- making and attending appointments,
- understanding which physical activities you can enjoy
- learning how to talk with your medical team.

With the physical changes that come with adolescence, it's also a good time to talk with your healthcare team (especially your cardiologist) about any adjustments to your health care plan (e.g. medicines, timing of appointments) that may be beneficial.

Adolescence is a time of rapid biological, psychological, cognitive and social change.

Relationships young people have with their parents, teachers and other adults may change during adolescence; however, these relationships are still fundamental to positive development.

Changes in adolescence

Physical changes

Puberty is the time when a young person's sexual and reproductive organs mature. Before any physical changes happen, the body starts to make hormones that trigger sexual development and growth.

Puberty starts at around 10 years for girls and 12 years for boys, give or take a year or so. Physical changes can be seen at around 10 to 14 years for most girls and around 11 to 15 years for most boys. A lot of emotional changes happen alongside these physical changes and young people also start to think differently. Young people's bodies start to grow taller, hair growth, change shape eg. hips and breasts and girls will start to get their periods. Some young people will experience skin changes including acne. You can read more about puberty [here](#).

Cognitive

Young people's brains are still developing and adolescence is a time of significant brain development. One part of the brain in particular - the pre-frontal cortex - which sits at the front of the brain, plays an important role in decision-making. This part of the brain enables people to think about the consequences of their actions, solve problems and control impulses. It is not unusual for young people to act on impulse, engage in risky behaviours, or struggle to manage their emotions. Young people can be supported in strengthening their cognitive capacities and guiding their behaviours.

Psychological and Social

In adolescence, young people are continuing to develop their sense of identity, their relationships and their independence. Adolescents may explore new relationships, or try new educational, vocational or recreational activities. It's not uncommon for young people to withdraw from family activities and prefer to spend time with friends; however, relationships with trusted adults are still important for positive development. **Adolescence is the peak time for onset of mental health conditions.** Young people and their families need to be aware of the symptoms of mental health issues, and know how to respond and where to get help.

Mental health and wellbeing

Young people's mental health is an important aspect of overall health. This means discussing how you are feeling with your medical team. It is particularly important to discuss feelings of anxiety, stress or feeling down for long periods of time including if you are finding it hard to do your usual activities.

If you are concerned about your mental health ask for help.

There are excellent mental health services available for young people either in person, or over the phone. There are a range of people you can talk to depending on what support you require, such as youth workers, counsellors and psychologists.

A strong support network is vital for young people and is one of the many aspects of healthy adolescent development. Social support is a protective factor for young people, increasing resilience, helping to reduce stress and improve mental health and wellbeing.

Finding support

Your health care team are an excellent resource for understanding adolescent development and your heart condition. Think about someone on your medical team that you feel you can talk to, or someone you trust, this might make these conversations easier for you. Maybe you could bring along a trusted friend or family member so you feel supported to speak about how you are feeling or issues that are concerning you.

Your GP can assist you with many lifestyle, general health and mental health issues and point you to appropriate services.

Links to services and further information on mental health

There are a range of services available to assist in learning about mental health as well as access to services, here are some suggestions:

Kids helpline

1800 55 1800

kidshelpline.com.au

Headspace

headspace.org.au

Lifeline

13 11 14

lifeline.org.au

Reachout

au.reachout.com

Reproductive Health

Reproductive health is an integral part of overall development for young people. Young people with a chronic health condition such as heart disease will typically experience normal reproductive development such as puberty, desire for romantic relationships and desire to have children. Reproductive health is an important topic for young people to discuss with a trusted member of their health care team to understand the impacts of their heart condition on their reproductive health, and to explore topics such as safe sex and contraception. Some young people may have delayed cognitive development due to their heart condition. The treating medical team will be able to provide information on this topic.

Risky Behaviours

Developing a sense of identity is a key developmental milestone of adolescence. Our personality, relationships, behaviours, values and beliefs, culture, and gender and sexual orientation all shape our sense of identity. Identity is often developed through experimentation, where a young person tries things to learn more about who they are and what they like (and don't like). Looking for new experiences is normal for young people, and can lead to thrill-seeking and risky behaviours.

Risky behaviours may include:

- Alcohol use
- Tobacco smoking
- Recreational drug use
- Safe and unsafe sexual activities

For young people with heart disease, risky behaviours can pose additional risks, like the interaction of alcohol with medications, drugs and heart disease. Having open conversations with your medical team will help you to obtain information to make informed choices and look at ways to reduce risk and harm.

Exercise and healthy lifestyle

Eating nutritious food and getting regular exercise are important at every stage of life, but engaging in these activities during adolescence can help to set up healthy habits for the rest of one’s life. For young people with heart disease, this is no exception. Studies demonstrate the benefits of a physically active lifestyle for children, young people and adults with heart disease. As always though, **it’s important to speak with your health care team (especially your cardiologist) about the types of exercise that might be best for you!**

Transitioning from paediatric to adult cardiac care

All young people work their way through puberty and adolescence. This is a time of transition with your health care too – you will be starting to manage your condition and move from the paediatric hospital to adult care setting.

There are many differences between the services provided at a children’s hospital (paediatric services) and adult services. A key difference is that child health services are family-focused, with parents and carers taking the lead responsibility for care. In adult services, young people, with the support of family and friends will gradually move to independently manage their health care and be actively engaged in the management of their care. This requires a new set of skills, information and support.

Young people with heart disease will transition into the adult healthcare system over a period. The actual transfer of care from paediatric to adult cardiac care usually occurs at the age of 18 years. Within some hospitals, transitional programs are available to assist in preparing and empowering young people to manage their own health and facilitate a smooth transfer from paediatric to adult health services.

The four key phases:

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| Introductory/Planning Phase (Approximately 12-15 years old) | Patients are introduced to the concept of transition, starting the information exchange, and assessing their knowledge of their medical condition and how to manage it. |
| Preparation Phase (Approximately 15-18 years old) | Patients develop a transition plan and are assigned a transition lead (a person who will help to manage the transition process). During this phase, confidentiality and the rights and self-advocacy are explored. |
| Transfer Phase (18-19 years old) | Readiness to transfer and all relevant information is sent to the new adult care team. The patient has their last visit with their paediatric cardiologist and will meet and start having appointments with their adult cardiologist. |
| Evaluation Phase (6-8 months following transfer) | The patient and their parents and carers can provide feedback about the transition and transfer process and their experience. |

From Royal Children’s Hospital, Melbourne Transition Support Services

To learn more about Teen Transition, follow the links below:

Royal Children’s Hospital, Melbourne

https://www.rch.org.au/transition/for_young_people/For_Young_People/

Cardiac Teen Transition

<http://www.ctt.org.au/>

Trapeze

<http://www.trapeze.org.au>

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.



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Medtronic Australasia has supported the development of this factsheet for educational purposes, with no influence on the clinical content.

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