

Childhood congenital heart disease and mental health

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Overview

This fact sheet provides basic information about the links between congenital heart disease (CHD) and mental health difficulties in children. It can be used as an accompaniment to the [Understanding child mental health and chronic physical conditions](#) e-learning course, which highlights the links between chronic illnesses/conditions in childhood and associated mental health difficulties.

This fact sheet covers general information about congenital heart disease, as well as details such as prevalence in Australia and the implications of the illness for children, including mental health impacts. Some content also pertains to adults.

Key points include:

- Congenital heart disease is an umbrella term for defects of the heart, heart valves or central blood vessels that are present at birth.
- Around 2,400 babies in Australia are born with congenital heart disease each year (approximately one in 100 live births).
- Children with congenital heart disease can require surgery, heart transplants and ongoing hospitalisation, while others require medication. Congenital heart disease may also have significant impacts on quality of life and mental and physical health and wellbeing, and may reduce life-expectancy.
- Support from family and health professionals can help children manage their congenital heart disease, enhance their quality of life, and improve their mental health and wellbeing.



What is congenital heart disease?

Congenital heart disease (also known as congenital heart defects) is a collective term for defects of the heart, heart valves or central blood vessels that are present at birth. Congenital heart disease can take many forms, such as holes between the pumping chambers, faulty valves, and narrowing of major blood vessels such as the aorta (Australian Institute of Health and Welfare [AIHW], 2019). It is the most common birth defect in Australia (Parker, Houghton, Richard, & McKeever, 2020).

Congenital heart disease can occur at different ages, although the symptoms vary between people who have simple or mild congenital heart disease, and those with moderate to complex congenital heart disease.

Simple or mild congenital heart disease is usually not diagnosed in pregnancy, nor in the first few months after birth, but may be diagnosed when children are older.

Children with simple or mild disease will usually present with:

- abnormal heart rhythms
- swelling
- fainting
- fatigue
- abnormal breathing; and/or
- dizziness.

Moderate to complex congenital heart disease is more serious and is often diagnosed in pregnancy or soon after birth. Children with more complex disease may have symptoms including:

- bluish lips, fingers, toes, skin and nails
- breathlessness or trouble breathing
- low birth weight
- poor feeding and weight gain; and/or
- chest pain (AIHW, 2019; Raising Children Network, n.d.; Victor Chang Cardiac Research Institute, n.d.).

What is the prevalence of congenital heart disease in Australia?

Around 2,400 babies in Australia are born with congenital heart disease each year (around one in 100 live births), with the majority of cases diagnosed in infancy and early childhood.

Congenital heart disease in Australia

In 2011, about 26,000–32,000 adults in Australia had congenital heart disease (AIHW, 2019).

What are the implications of congenital heart disease for the child?

About half of all babies with congenital heart disease in Australia need surgery or cardiac catheterisation, to reduce the effects of, or repair, the specific defect in their heart (AIHW, 2019; American Heart Association, n.d.; Blue, Kirk, Sholler, Harvey, & Winlaw, 2012). For some, congenital heart disease can be managed through medication and treatments that manage oxygen levels and blood pressure. For those with severe and complex congenital heart disease, ongoing hospitalisations, corrective surgery, heart transplants and compassionate care – e.g. pain management, palliative and/or end-of-life care – may be required across the lifespan. The largest number of hospitalisations for congenital heart disease occurs in infants under one year old (AIHW, 2019).

People living with congenital heart disease, particularly more complex CHD, are at an increased risk of disability, including:

- autism
- language delays
- attention difficulties
- motor skills impairment
- attention deficit hyperactivity disorder; and
- physical and intellectual disability (Gonzalez et al., 2021; Wilson, Smith-Parrish, Marino, & Kovacs, 2015).

Having complex congenital heart disease or surgery during the first year of life can impact on cognitive and executive functioning (Sanz et al., 2018). This, in turn, may result in severe attention issues, working memory difficulties, difficulties with organising and planning, and difficulties in regulating behaviours (Wilson et al., 2015).

Treatment affects the child's quality of life and their ability to participate in school and other activities (Razzaghi, Oster, & Reefhuis, 2015). Many children with complex congenital heart disease receive supports including tutoring, early intervention, occupational therapy, or special education (Wilson, et al., 2015).

Congenital heart disease is a leading cause of death among Australian infants, with 46% of all CHD occurring in infants under one year of age (AIHW, 2019). The three types of congenital heart disease that result in the highest number of deaths are hypoplastic left heart syndrome, ventricular septal defect, and atrial septal defect (AIHW, 2019).

What are the mental health impacts of congenital heart disease?

Internalising difficulties (e.g. anxiety, depression, somatisation) or externalising difficulties (e.g. behaviours, aggression) are experienced by 15–25% of children with congenital heart disease (Gonzalez et al., 2021; Wilson et al., 2015). Children with simple/mild congenital heart disease aged 4–9 years are five times more likely to have a diagnosis of anxiety and/or depression than children without congenital heart disease; while those who have complex types of congenital heart disease are seven times more likely (Gonzalez et al., 2021). Findings of a systematic review suggest that infants as young as 2–3 months with congenital heart disease show signs of risk for emotional, social and behavioural problems (Clancy, Jordan, de Weerth, & Muscara, 2020).

What impact does congenital heart disease have on families?

When a child is diagnosed with congenital heart disease, it also affects the family unit. Families may experience financial hardship, and may need to work fewer hours or stop working altogether to care for the child (McClung, Glidewell, & Farr, 2017). Parents of children with congenital heart disease are more likely to experience anger, anxiety, distress, depression and hopelessness than other parents (Jackson, Frydenberg, Liang, Higgins, & Murphy, 2015) – and some may require mental health services (McClung et al., 2017). Psychological symptoms in family members are especially noticeable around the time of diagnosis of congenital heart disease and during surgery, and can include post-traumatic stress disorder (Woolf-King, Anger, Arnold, Weiss, & Teitel, 2017).



Siblings of children with congenital health disease may take on more household work (Parker et al., 2020). They may also become more involved in the caretaking of their sibling – a dynamic which is particularly apparent between sisters (Parker et al., 2020). They may also engage in fewer social activities, and experience reduced school performance (Parker et al., 2020). Siblings may also feel afraid of getting too close to their sibling with congenital heart disease, left out, jealous, resentful, and insecure (Wray & Maynard, 2005). Siblings may also experience anger, intolerance, anxiety and depression (Wray & Maynard, 2005). These impacts can become worse as siblings grow older (Caris et al., 2018), and are more likely to occur if the sick child has more complex congenital heart disease – and even more likely when the sick child has undergone transplants (Wray & Maynard, 2005).

Conclusion

Congenital heart disease can have significant implications for children's overall development and wellbeing, including ongoing mental health concerns. Early identification of these concerns and access to professional services, including allied health practitioners and social workers, offers the potential to alleviate the challenges for children and their families. Further information about the impact of chronic conditions on mental health can be found within the [Understanding child mental health and chronic physical conditions](#) e-learning course.

Where can I go for further information on congenital heart disease?

[HeartKids](#)

National not-for-profit organisation solely focused on supporting and advocating for all people impacted by childhood heart disease.

[Australian Institute of Health and Welfare](#)

Independent statutory agency, producing authoritative and accessible information and statistics leading to better health and wellbeing for all Australians.

[Heart Foundation](#)

Peak body working to improve heart disease prevention, detection, and support for all Australians. Their 13 11 12 helpline is open 8:30 am to 5:30 pm Monday to Friday, except public holidays.

[Heart Support Australia](#)

National not-for-profit organisation providing support, information, and encouragement to people who have been affected by a heart event.

[Pregnancy, Birth & Baby](#)

Website with information for parents on the journey from pregnancy to preschool.

[Australian Birth Defects Society](#)

Non-profit organisation run by a group of professionals, which aims to inform both the public and medical professionals about the latest news, academic findings, facts and advice for pregnant women and families.

What are some other supports for children and families?

[Beyond Blue](#)

Beyond Blue provides information and support to help everyone in Australia to achieve their best possible mental health. The service supports those experiencing depression, anxiety or going through a difficult time. The phone service 1300 224 636 operates 24/7, while the website offers online chats, email support and online forums.

[GP and psychologist](#)

Families can consult with their local health professional to get access to specialised support.

[Healthdirect Australia](#)

Healthdirect is a national, government-owned, not-for-profit organisation supporting Australians in managing their own health and wellbeing through a range of virtual health services. Health advice is available on 1800 022 222.

[Kids Helpline](#)

Kids Helpline is a free, private and confidential 24/7 phone and online counselling service for children aged 5–12 years and young adults aged 18–25. Qualified counsellors are available via phone on 1800 551 800 or via WebChat or email.

[Lifeline](#)

Lifeline is a national charity providing all Australians experiencing emotional distress with access to 24-hour crisis support and suicide prevention services. Available via phone on 13 11 14.

[Parentline](#)

Parentline is a confidential telephone service providing professional counselling and support in Queensland and the Northern Territory. Available via phone on 1300 301 300.

[Raising Children Network](#)

Raising Children Network is a comprehensive and trusted online resource for parenting information. A website includes information on children's health and wellbeing across the ages. It includes videos, fact sheets and downloadable toolkits on child development, behavioural problems and health issues.

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