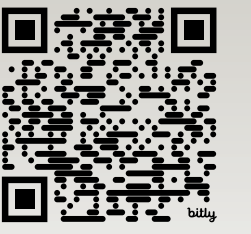


# Childhood-onset Heart Disease

MISSING  
SCHOOL



Childhood-onset heart disease (CoHD) is the collective term for the spectrum of heart conditions that affect the heart's ability to work efficiently. Heart defects and conditions experienced from birth are known as **Congenital Heart Diseases (CHD)**. **Acquired Heart Disease** refers to conditions that arise later in childhood, commonly as a result of infections or exposures.



## Health condition

- Lifelong condition, often requiring surgery and ongoing care
- Symptoms range from mild to severe
- Susceptibility to illness and neurodevelopmental delays
- Comorbid conditions further complicate health and development
- Often invisible, making impacts and limitations hard to see
- Extended or multiple hospital stays, and medical/surgical interventions can delay developmental milestones



## Student population

Affects **one in 100 children** in Australia

**Eight children born** with CoHD daily

Approximately **40,000 school-aged children in Australia live with CoHD**

On average, **20 students** will have CoHD **in a school of 2000**

*"Heart kids can miss a lot of school, depending on the individual. Admission to hospital, surgery, follow-up medical appointments and accessing ongoing care and reduced immunity. So that can cumulatively over a year result in a not insignificant proportion of the school year missed."*



## School absence patterns

- Hospitalisations, surgeries and follow up medical appointments can lead to significant absences
- Students may stay home during outbreaks due to low immunity, increasing missed days
- Estimated average absence of 5-10 days per term



## Challenges for students

- Anxiety and mental health challenges, particularly in the teenage years
- Neurodevelopmental delays can occur due to prolonged hospital stays during infancy
- Higher level and prevalence of bullying of CoHD kids
- Social disconnection due to prolonged absences and transitions



## Challenges for families

- Parents often feel guilt and grief after a CoHD diagnosis
- Siblings may experience anxiety or behavioural challenges
- Family separation during care periods disrupts routines
- Families, especially in remote areas, face extended separations and logistical stresses



## What schools should know

- CoHD is a lifelong condition. Misconceptions like, 'They're fixed after surgery,' can undermine support
- Develop individualised learning and health plans for heart kids
- Ensure continuity of education during absences using technology or alternative programs
- Students with CoHD may have invisible challenges that limit participation
- Make accommodations for physical limitations, such as fatigue and restricted participation in activities
- Provide classroom aids to assist students reintegrating after extended absences
- Educate teachers and peers about CoHD to foster understanding and inclusivity
- Involve all teachers, not just classroom teachers, in understanding the student's needs.
- Address social isolation by developing strategies to maintain connection to friends and peers during absence and help rebuild relationships on return from extended absences
- Recognise the heightened risk of bullying and implement proactive measures



### HeartKids

The only Australian charity dedicated to providing lifelong support, resources, and advocacy for the 250,000 people impacted by childhood-onset heart disease.

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