

Understanding childhood-onset heart disease (CoHD): a guide for educators



This factsheet provides educators and school staff with essential information about CoHD to better support students in school. CoHD can impact a child's development, daily activities, and overall quality of life, so awareness and support from schools are highly important in ensuring children with CoHD can thrive academically and socially.



What is CoHD?

CoHD refers to a range of congenital or acquired heart conditions diagnosed in children. These conditions can affect the heart's structure, function, or rhythm.

Congenital Heart Disease (CHD): Includes conditions present at birth that affect the heart's structure, such as holes in the heart or irregularities with blood vessels and valves. The impact for individuals varies depending on the severity or number of conditions.

Acquired Heart Conditions: Develop after birth due to factors such as illnesses, infections, chronic diseases, or medications affecting the heart. Examples include Kawasaki disease and rheumatic heart disease.

You can learn more about the various types of CoHD via the HeartKids website heartkids.org.au/cohd-condition-types

Impact on Education and Participation

Children with CoHD can encounter unique challenges that can affect their educational experience and participation in school activities. These challenges can vary significantly from one student to another, depending on the severity of their condition and the treatments they undergo. While not all students with CoHD will experience significant learning difficulties, it is important for schools to recognise and address potential issues proactively.

Understanding the possible impacts can help educators create a more supportive and inclusive environment for these students.

Children with CoHD may face:

- Fatigue and difficulty concentrating due to the heart's reduced ability to pump blood efficiently.
- Missing school due to medical appointments, illness or surgery.
- Anxiety about their health, physical abilities or appearance (i.e. from surgical scars or colour changes) which can distract from learning and participation in school activities.
- Neurodevelopment delay related to the impact of their heart condition.

Creating an inclusive learning environment

Schools and teaching staff can support children with CoHD by following established guidelines on inclusive education and support for students with disabilities.

Creating an inclusive learning environment for children with CoHD may include implementing individualised learning plans, allowing additional rest breaks, and accommodating unique needs. Educators can ensure all students thrive by making reasonable adjustments to teaching methods, curriculum, and classroom settings, as outlined in the Disability Standards for Education (2005).

It's important all school staff responsible for a student's care are aware of their condition and any necessary accommodations. For example, some students may need more frequent toilet breaks due to medication, and it is important for all staff to be accommodating of this need.

A collaborative approach involving the student, teachers, parents, and medical professionals ensures that all aspects of the student's health and educational needs are considered and met effectively. See the resources at the end of this document to learn more.

School Camps

Most young people with CoHD can attend school camps and benefit from these experiences. Ensure they have consulted their cardiologist or GP beforehand for their safety.



Surgery and absence

Teachers should be aware of the unique challenges children with CoHD face when undergoing surgery, taking time off school, or returning after an absence. It's important to provide additional academic support, offer flexibility with assignments, and ensure a welcoming and understanding classroom environment to help these students reintegrate smoothly and maintain their educational progress. The organisation Missing School has a variety of resources to aid you in supporting students who experience school absence due to illness. Learn more at missingschool.org.au.



Neurodevelopmental delays and CoHD

Children with CoHD may be at an increased risk for neurodevelopmental challenges. Factors influencing outcomes include the severity of the heart defect and the need for surgical interventions. Some children may exhibit difficulties in motor and cognitive skills, as well as behavioural and emotional challenges. Schools and educators can play an important role in monitoring delays and providing feedback to parents and caregivers.



Immuno-compromised students

Some children with CoHD may have weakened immune systems due to their condition or treatments, making them more susceptible to infections. Be aware some students may need time away from school during periods where instances of common illnesses are more frequent in the school population.

Supporting health and safety

Teachers play an important role in keeping an eye on the health and wellness of students with CoHD. Being observant and responsive to any changes in a student's health can make a significant difference to the child's overall health and safety. HeartKids have dedicated **CoHD Student Information and Emergency Plans** [[link to docs when live](#)] parents can complete with their child's doctor, ensuring that schools have all the specific information they need to support the child effectively.

For all students with CoHD, it's important to be aware and responsive if your student experiences any of the following:

- Shortness of breath
- Dizziness or fainting
- Chest pain
- Palpitations or feeling of a racing heart
- Unusual fatigue
- Swelling in the legs, ankles, or feet
- Turning blue



Other factors to be aware of:

- **Hot/Cold weather:** In particularly hot/cold weather, some children with heart conditions may become breathless quickly or may need to regulate their temperature during breaks or outdoor activities.
- **Exercise:** Some children with heart conditions may get tired quickly when exercising and may be restricted in the type of physical activity they can do. Consult with the child's parents, cardiac liaison nurse, or cardiologist.
- **Medications:** Be aware of the medications a child is taking, their purposes, and any side effects. It may be useful to draw up a health care plan with parents if medication is needed during school hours.

Communicating with your student and their parents

Effective communication between teachers and parents of children with CoHD, is vital for ensuring consistent care and support. Regular and open dialogue helps in understanding the child's specific health needs and activity levels.

Teachers should refer to notes from parents and review the child's health documents to check for prescribed activity levels. It's important not to assume a child will need to sit out of any activities or that their symptoms are severe without complete information from parents and health professionals. Understanding and respecting a child's ability to determine their own activity levels is also highly important.

To ensure a supportive environment for children with CoHD:

- Maintain open and empathetic communication with the child and their parents.
- Regularly update parents on their child's progress and any concerns.
- Involve parents in the development of individualised education plans.
- Utilise resources provided by HeartKids for additional guidance.

CoHD can significantly impact a child's school experience. Awareness, support, flexibility and effective communication are vital to creating a safe and inclusive environment for all students.



HeartKids Resource Library:

<https://www.heartkids.org.au/resource-library>

HeartKids Resource Library is a one-stop-shop for information and resources for Childhood onset Heart Disease (CoHD), congenital heart disease and acquired heart disease.

Missing School: [Missing School](#)

Inclusive Education: [AITSL Inclusive Education](#)

Disability Standards for Education (2005): [Disability Standards for Education](#)

Supporting Students with Disability, Department of Education:

[Supporting Students with Disability](#)

AITSL Standards: [Australian Professional Standards for Teachers](#)

About HeartKids

HeartKids is the only Australian not-for-profit organisation dedicated to supporting and advocating for families impacted by childhood-onset heart disease (CoHD).

HeartKids provide support and resources for families of children with heart disease. To learn more about supporting students with CoHD head to [heartkids.org.au/support/schools-and-workplaces/](https://www.heartkids.org.au/support/schools-and-workplaces/)

You can find more resources design specifically for young people with CoHD here: www.heartkids.org.au/support/young-people/



HeartKids Helpline and webchat

The HeartKids Helpline offers support and guidance to those impacted by Childhood-onset Heart Disease, including families, caregivers, health professionals, and anyone seeking information or referrals. Our team is here to listen and assist without judgment, ensuring everyone feels supported.

Contact the Helpline on **1800 432 785** or speak to our staff on **webchat** via [heartkids.org.au](https://www.heartkids.org.au).

[heartkids.org.au](https://www.heartkids.org.au) | [1800 432 785](tel:1800432785) | office@heartkids.org.au | © HeartKids

This fact sheet was reviewed and updated by HeartKids in June 2024. It was endorsed by the HeartKids 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 or your family's health. Have feedback about our resources? Contact office@heartkids.org.au.