HeartKids

CHD and Neurodevelopment

Information for families on how congenital heart disease (CHD) can impact development in children.

What is Neurodevelopment?

Neurodevelopment is a term that describes the brain's development of neurological pathways that influence performance or functioning. It is the skills children acquire during infancy, childhood and adolescence, and how they use those skills in different situations and environments.[1] How children develop is influenced by interactions between biological, genetic and social factors and the environment.

It includes things like:

- motor skills
- communication, play and social skills
- learning, reading and focusing
- behaviour and emotions

Children with neurodevelopmental difficulties may need to work harder to develop some of these skills.

90%
of children born with a congenital heart defect will survive into adulthood.[2]

Most children with CHD have a normal neurodevelopmental profile.[3]

What is the connection between CHD and neurodevelopment?[2-3]

As survival rates for CHD have improved, there has been an increasing focus on how CHD can impact neurodevelopment and quality of life.

As a group, children with complex CHD are at an increased risk of developmental difficulties compared to those with simple or no CHD.

This does not mean that all children with complex CHD have these difficulties. Many do not. Similarly, a small percentage of children with mild CHD may experience neurodevelopmental challenges.[2]

My daughter Mahli-May is six now and mostly healthy. However, her [CHD] has affected her development.

She can be quite impulsive and has certain unusual traits, but they work for her. Mahli's so different. She doesn't fit into any box. She's so funny, and she's smart in a lot of ways.

— **Monique,** Mum to Mahli-May

Why are children with CHD at an increased risk?

Risk factors of developmental difficulties that can be more common in children with CHD, particularly complex CHD, include[3-5]:

- Altered blood flow to the brain before and after birth
- Cardiopulmonary bypass (open heart) surgery as an infant
- Extended time in the intensive care unit (ICU) or in the general hospital environment
- Genetic syndromes or anomalies

These factors can vary across children.

What are the indicators and impacts of developmental issues?[3-6]

Infants and toddlers

May show delays in their motor skills, like crawling and walking. They will often catch up to their peers, but monitoring and early intervention is still beneficial. Delays in their feeding, early communication and play skills may also occur.

Early childhood and primary school

This is a period of significant growth and skill development. They may show difficulties with attention, planning and organisation, memory, problem solving and managing emotions. They may experience challenges with more complex communication. These issues can impact how children learn and socialise with friends and peers.

Adolescence and high school

Adolescence is a time of increasing academic and psychological demands. Developmental and behavioural concerns seen in childhood can continue into adolescence and new concerns can also occur. These may impact on daily living skills, social relationships, academic achievement and workplace participation.

For some adolescents, the experience of chronic illness can also impact their mental health, wellbeing, and self-esteem.

What do I do if I have concerns about my child's development?

If you have concerns, address them with your GP, pediatrician, cardiologist, teacher or school psychologist. They may refer your child for further assessment and support.

For some children with CHD, developmental concerns may be subtle and new challenges may arise over time. Children may also experience new difficulties as they grow. Ongoing monitoring of your child's development is recommended to support early identification and timely intervention.

Facilitating positive relationships for your child and opportunities for them to participate are important ways to support their development. Forming a good relationship with your child's school is also beneficial. This helps to create a supportive school environment.

What type of interventions are available?

This depends on the type of developmental difficulty your child is experiencing.

You may work with:

- Paediatricians
- Physiotherapists
- Occupational therapists
- Speech pathologists
- Psychologists
- Play therapists or child life therapists
- School staff and teachers
- Other community or educational services

Maddie has just started play therapy to help her work through her emotions about her heart and surgeries.

The play therapist comes to her school for the sessions.

The therapist flags any issues directly with the teacher and advocates for my daughter at school. It has taken some of the pressure off me.

— **Hannah,** Mum to Maddie

Is my child eligible for the NDIS?[8]

The National Disability Insurance Scheme (NDIS) funds support for children younger than 7 with developmental delay and support for children and adults with a disability. Support can include NDIS plans, or assistance to connect with community and mainstream supports to facilitate early intervention. CHD is not covered by the NDIS. Speak to your GP or Paediatrician for further information.

References

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[7]Ilardi D, Sanz JH, Cassidy AR, Sananes R, Rollins CK, Shade CU, Carroll G, Bellinger DC. Neurodevelopmental evaluation for school-age children with congenital heart disease: recommendations from the cardiac neurodevelopmental outcome collaborative. Cardiology in the Young. 2020 Nov;30(11):1623-36.

[8]Raising Children Network NDIS FAQS https://raisingchildren.net.au/disability/ndis/aboutndis/ndis-faq

Neurodevelopmental care is a priority in the Australian National Standards of Care for Childhood-onset Heart Disease.

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This fact sheet was reviewed and updated by HeartKids in March 2023. 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. Got some feedback about our resources? Go to: heartkids.org.au/feedback
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Where to find more information and support

HeartKids

heartkids.org.au

Learn more about CHD and the support HeartKids can offer you.

1800 432 785

Call the HeartKids Helpline for support and guidance.

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