

Supporting neurodevelopmental care



This factsheet collates useful resources to help support and educate carers around the neurodevelopmental impacts of childhood-onset heart disease (CoHD). It provides valuable supports to help carers maximise outcomes for their children, participate actively in care and support their family's well-being.

Understanding the impacts of CoHD on Neurodevelopment.

Below are some resources that introduce how CoHD impacts Neurodevelopment and what can be done to improve outcomes.

Scan or click on QR code to view resource.

Congenital Heart Disease (CHD) and Neurodevelopment

This factsheet provides a simple introduction and overview of neurodevelopment for carers of children with CHD.



CHD and Neurodevelopment – HeartKids From the Heart Podcast

Professors Rob Justo and Will Parsonage introduce the impacts of CHD on Neurodevelopment.



Mended Little Hearts – Neurodevelopmental issues in children with CHD

This is an excellent USA resource covering all aspects of CHD, with this link providing access to the section on Neurodevelopment.



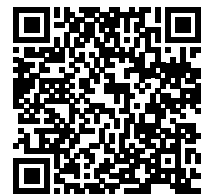
Understanding and tracking development milestones

Below are resources that will help you to understand and track typical developmental milestones for your child. These can help you identify problems with neurodevelopment if they arise, so that you can raise these concerns with a health professional. Through the early identification of neurodevelopmental problems, supports can begin as early as is possible to help improve neurodevelopment outcomes for your child.

Scan or click on QR code to view resource.

Center for Disease Control (CDC)

Online resource providing guidance on developmental milestones.



CDC Milestone Tracker App

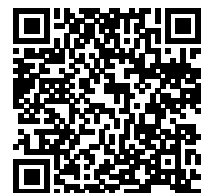
Free App for assessing and recording developmental milestones for your child. Both Android and IOS versions are available.

This app has excellent videos of how to test development milestones, provides easy logging of development and provides alerts if milestones are not met. It acts as a developmental record that can be easily shared with treating health professionals, such as your paediatrician.



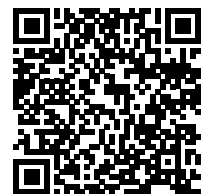
Raising Children

Provides developmental milestone guidance. This is an excellent all-round resource for parenting.



Starting Blocks

This is an Australian government resource with advice for parents on early education and care. The QR code provides a link to typical developmental milestones.



Early identification of autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD)

Children born with CoHD have an increased risk for ASD and ADHD. Whilst this does not mean that your child will develop either of these disorders, it is important that those who are affected are identified early so that interventions can begin to help them achieve their best outcomes. As their carer, and the person who knows your child best, you play an important role in the early identification of ASD and ADHD. Below are some resources to help you identify typical signs. If you are concerned your child is showing signs, raise this as soon as possible with your GP/Paediatrician or cardiac care team.

ASD signs and symptoms may begin to be more easily recognised from **12 months of age**, and even before in some children.

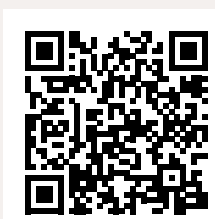
ADHD may be present from birth however, early recognition is difficult as many core behaviours and symptoms (inattention, hyperactivity and impulsivity) are part of typical developmental milestones in pre-school years. It may not be easily recognised until your child begins school, and it is important to listen to feedback from professionals such as teachers, on how your child is behaving in different environments outside of the home.

The resources below provide examples of typical signs and symptoms to look out for in both of these disorders.

Scan or click on QR code to view resource.

Raising Children

This website has excellent resources on how to identify ASD early, including videos from carers on what signs to look out for. The QR codes provide a link to the website and a video of carers sharing their experiences on early identification.



Raising Children

Provides excellent resources on early identification of ADHD.



Better Health Channel

Provides excellent resources on early identification of ADHD.



Supporting Neurodevelopment

As a carer you play an essential role in the general development of your child. Through your day-to-day interactions you can participate in their development and the building of skills with your child.

Building Brains and Bodies

This NSW government resource provides videos to help carers learn how to participate in building developmental skills with their children.

Scan or click on QR code to view resource.



Financial and travel supports

Attending appointments to support the neurodevelopment and general care of your child can be difficult for some carers who may have financial difficulties, or need support in other ways, such as accommodation. The resource below can help connect you with necessary supports.

HeartKids Australia

HeartKids provide access to support services within the CoHD community and can help link you in with financial supports. Each state has different provisions for travel and accommodation support. Other financial supports may also be available to you. Your treating health professionals should be able to help you access these supports. Alternatively The **HeartKids Helpline** can help you navigate and find supports.

Scan or click on QR code to view resource.



Call the HeartKids Helpline on 1800 432 785 for support and guidance, or contact HeartKids online (use or click on the QR code to navigate to the support page).

Mental Health Supports for Carers

The mental health of carers and family members can affect the neurodevelopment of the child they are caring for. Untreated maternal mental health issues during pregnancy can affect the neurodevelopment of the unborn child. If you or a family member are experiencing mental health problems it is important that you seek help, advice and support and talk with a qualified health professional or counsellor as soon as is possible. Below are some suggested resources to help you find support.

Scan or click on QR code to view resource.

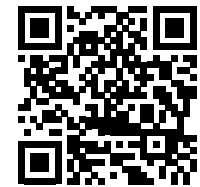
Mental health treatment plans

This link provides guidance for carers/individuals on how they can access mental health treatment plans.



Carer gateway

This is a government resource that helps link carers into counselling, peer group supports and other mental health supports. It can provide tailored supports and offers access to respite care.



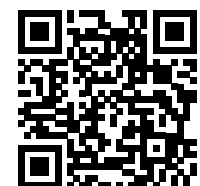
Carers Australia

Carers Australia provide short-term counselling and emotional and psychological support services for carers and their families in each state and territory. Call: 1800 242 636 or visit the website by scanning or clicking on the QR code.



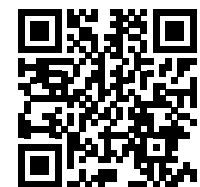
HeartKids Australia

HeartKids provide access to support services within the CoHD community and can help connect carers not only with mental health services but also with others who are on, or have recently been through, the same journey. By contacting the helpline on **1800 432 785**. HeartKids can put you in touch with the right kind of support. The Helpline is available during business hours (9am to 5pm, Monday to Friday). There is also an online form to fill outside of these hours and a live chat service.



Beyond Blue

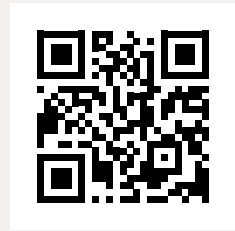
Beyond Blue provide mental health support, information and resources online or by phone. It provides online chat, online forums and a 24/7 Helpline: **1300 22 4636**.



Scan or click on QR
code to view resource.

Well Mob

Designed for Aboriginal and Torres Strait Islander People. Well Mob has a collection of social, emotional and cultural wellbeing online resources.



13 Yarn – Website

Mental Health support service run by and for Aboriginal and Torres Strait Islander peoples. Call **13 92 76**.



MensLine Australia

Provides mental health support targeted at men. Call **1300 78 99 78**.

