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Supporting Development in Children With Congenital Heart Disease

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Children with congenital heart disease (CHD) are exceptionally resilient. After extensive surgeries and hospitalizations, they typically go on to live full, meaningful lives. However, some children with CHD experience developmental and learning differences and benefit from extra help to succeed in school, social relationships, and future employment.¹

Why Are Children With CHD at Higher Risk for Developmental Differences?

CHD can result in changes to blood flow to the brain before and after birth, and this might affect brain development. Studies have found that the brains of children with some forms of CHD are less mature at birth. Children who have long hospital stays or other complications (premature birth or genetic/neurologic conditions) are also at risk. Studies are underway to better understand why children with CHD are at risk and how these risks can be decreased.

Does My Child Need Neurodevelopmental Follow-Up?

Children typically do best when developmental delays and learning differences are identified and addressed early; however, it is never too late for evaluation or intervention. For children with complex CHD (those requiring open-heart surgery during infancy) or other risk factors or complications, the American Heart Association and the American Academy of Pediatrics recommend routine neurodevelopmental assessment as an essential part of cardiac care.¹ Assessment should also be provided for any child with CHD and developmental concerns. You know your child best; trust your instincts and talk with your doctors and teachers if you think your child is not developing important skills. Ask your cardiac team about a cardiac neurodevelopment program (or a general neurodevelopment program, if a cardiac-specific program is not available), which may be located

within the hospital where your child had heart surgery.

What Should I Watch For?

Concerns can arise at different developmental stages. See the Table for milestones and possible concerns. Infancy is a time of rapid growth. In preschool, children build independence and become great learners. School-age/adolescent children are building an academic and social foundation for adulthood. Even children who have had no problems before may begin to struggle as demands increase over time. Ongoing reassessment is needed to identify and support changing needs.

What Can I Expect From a Neurodevelopmental Assessment?

Assessments provide a snapshot of a child's strengths and weaknesses in comparison with other children the same age. Repeated assessment helps to track change/improvements over

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Table. Milestones and Possible Problems by Developmental Stage

Age	Important Milestones	Possible Concerns
0–6 mo	Head control, rolling over, reaching toward objects with both hands Cooing, laughing, smiling Developing sleep/eating patterns	Dislike being on stomach, weak/overly tense muscles, using only 1 hand/side of body, trouble turning head Not vocalizing or responding to caregivers Difficulty calming and developing routines
6–12 mo	Sitting up, supporting weight on feet, grabbing objects Babbling, recognizing caregivers	Muscle weakness/tightness, not picking up small things Difficulty learning to chew/make sounds, no back-and-forth play, hearing/vision problems
1–2 y	Walking, eating with hands Speaking single words, following simple directions Preferring certain people, sleeping through the night, eating solid foods	Slow to walk Not speaking words or gesturing Difficulty eating solid foods, sleep problems, extreme fear of new situations or people
2–3 y	Running, jumping, stacking blocks, eating with fork/spoon Understanding most words, speaking 2-word phrases, pretend play	Poor coordination Trouble understanding, unclear speech, single words only, extreme or frequent tantrums
4–5 y	Increased independence with self-care skills, better coordination Speaks in full sentences Playing with other children, learning social rules, basic understanding of feelings Showing school readiness	Problems tying shoes, buttoning, snapping, or zipping, poor coordination Problems communicating or speaking clearly Trouble making friends, playing well with peers, participating in group settings Problems learning letters/numbers, holding pencil, cutting, short attention span, overly active
Kindergarten to 3 rd grade	Learning basic academic skills, keeping up with school work Forming friendships	Trouble with math facts, sounding out words, spelling, or handwriting, inattentive, trouble with multistep directions Trouble making/keeping friends, misunderstand social rules and other's feelings
Later elementary/middle school	Applying basic academic skills, keeping up with pace of learning, increased organization and independence Tolerating frustration and changes, managing emotions Reading subtle social cues, having good friendships	Trouble understanding what is read, slow/messy handwriting, slow keyboarding, puts off homework/takes much longer than peers to finish, forgetful/disorganized, makes careless errors Moody/worries, strong reaction to frustration No best friends, trouble relating to others, overly self-conscious about looks or grades
Teenage years to young adulthood	Knowing needs and communicating them to teachers/employers Completing school/job tasks and pursuing goals independently Actively participating in medical care, taking medicine with parent support (or independently) Engaging in good health habits Responsible/accountable, good behavioral control	Not asking for help or self-advocating Lack of initiation, parents need to help with goals, provide transportation Needing high level of support for medical care, forgetting to take medications, not understanding medical diagnosis Poor diet, limited exercise (despite encouragement and lack of restrictions) Engaging in risky behaviors, decreased participation in typical activities (driving, getting a job), withdrawn

time. For infants/toddlers, the assessment consists of play and structured games. For older children, it includes activities that resemble schoolwork. Parents and teachers may be asked to fill out questionnaires about learning and behavior. Recommendations are then made to support child development. For example, in young children, every state has an early intervention program that provides therapies (eg, speech or physical therapy) to help children meet their full potential. In older children/adolescents, therapies and academic supports can be provided in the school and outpatient community.

Your Role as a Parent

Families often say that children with CHD are evidence of miracles. As the family member of a child with CHD, you have already helped your child succeed by providing support, encouragement, and important resources. Regular neurodevelopmental assessment is an important part of care for children with CHD that will help your child continue to thrive.

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Disclosures

None.

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