



Neurodevelopmental Outcomes for Children following CHD Surgery

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The Journey of a Thousand Miles Begins....



- Transition from surviving to thriving
- >50% children will demonstrate differences in how the brain grows, organizes itself, and functions
 - This shapes how a child moves, learns, communicates, behaves, and processes information
- Changes in the how the brain develops often begins before birth
- Additional stressors around surgical repair of the heart can further affect the developing brain



Neuroplasticity

- Early childhood is a period of remarkable brain adaptability
- Time to capitalize on:
 - Enrichment and intentional exposure to opportunity
 - Deliberate attention to developmental skill development
 - Early intervention to maximize outcomes
 - Therapies to guide and coach families through process

Motor Development



- Gross motor delays affect nearly half of children
 - Head control
 - Rolling
 - Tummy time
 - Sitting
 - Crawling
 - Walking
- Fine motor delays affect approximately 1/3 of children
 - Hand-eye coordination
 - Reaching, grasping, and manipulation skills



Encouraging Motor Development

- Supportive positioning and stretching
- Tolerating movement and changes to positions
- Active play and minimizing use of containers
- Moving against gravity
- Floor play
- Tummy time
- Head and trunk control
- Activities to promote leg strength and power

Language and Communication Development



- 20-30% of children may present with language differences
- Risk for expressive (talking) and receptive (understanding) language delays
- Some challenges may be subtle early and emerge later in development
- Early language delays may also impact later literacy skills



Encouraging Language Development

- Recognize and respond to early communication
- Support early communication and language development
- Incorporate language into everyday routines
- Support enrichment of the environment through language models, songs, book reading, play
- Model clear speech, short sentences, not "baby talk"
- Encourage early use of sign language or picture boards to reduce frustration, build language and social connection

Thinking and Learning Development



- These challenges are not obvious in infancy
 - May emerge as developmental demands increase
- Encourage development through:
 - Problem solving through play
 - Joint attention
 - Reciprocal play
 - Independent play
 - Self-regulation
 - Self-soothe
 - Tolerate frustration
- Can lead to challenges later with attention, visual-spatial integration, executive functioning, and later academic achievement

Why is Feeding So Difficult?

Feeding difficulties are very common following cardiac surgery!



- Oral aversion from medical procedures
- Prolonged intubation
- Fatigue during feeding
- Breathing and swallowing coordination challenges
- Nausea and reflux from medication, withdrawal, and challenges with perfusion to the gut
- Aspiration
- Limited exposure to feeding opportunities
- Association with other negative experiences increases avoidance and aversion
- Taste or smell changes



Ways to Help Feeding Development

- Ensure feeding is safe, nurturing, and functional
- Responsive feeding strategies
- Keeping eating fun and low stress for everyone involved!
- Play with your food!
- Transition from tube feeding to oral feeding may take time and patience
- Keep feeding experiences positive
- Specialized evaluations by speech pathologists are often needed

Developmental Monitoring



- The American Heart Association recommends routine developmental evaluation at key stages:
 - Infancy
 - Toddlerhood
 - Preschool age
 - Kindergarten
- Role of occupational, physical, speech-language and feeding therapy, and FAMILY!
 - Therapies during hospital stay
 - Therapy support in the home and community
 - Early Childhood preschool
 - Family is the most important team member!

Key Takeaways



- ❖ Developmental challenges after heart surgery are common
- ❖ Challenges reflect how the brain develops under medical stress—not a child’s potential or a parent’s effort
- ❖ Early developmental activities and therapies can support:
 - Movement
 - Feeding
 - Communication
 - Learning
 - Play
- ❖ Parents play a critical role by observing, monitoring, and advocating for evaluations when needed
- ❖ With early support, many children make meaningful progress over time!



Resources

- CDC Milestone Checklists for tracking motor, language, and social milestones: www.cdc.gov/act-early/milestones/index.html
- CDC Milestone Tracker App: www.cdc.gov/MilestoneTracker
- ASHA Communication Development Norms for understanding speech and language expectations and feeding development: www.asha.org/public/developmental-milestones/
- Mended Hearts/CNOC family resources for CHD-specific developmental guidance and peer support: www.mendedhearts.org/about-us/about-mended-little-hearts/