Genetic Education Materials for School Success

Congenital Heart Defects

Table of Contents

Acknowledgment:

Genetic Education Materials for School Success (GEMSS) was created and maintained by an interdisciplinary team of genetic counselors, physicians, families, and students working with New England Regional Genetics Network (NERGN) and the Institute on Disability at the University of NH. Thank you to these amazing partners. This work was supported by HRSA grant UH7MC30778.

Disclaimer:

This is not intended to be medical or clinical advice. Any recommendations here should be reviewed for the appropriateness for your individual child and their unique situation. Also, please note that each document should include the date that it was last reviewed or updated. Research and guidelines that have been released after that date may represent more up-to-date recommendations.

Congenital Heart Defects

At a Glance

Congenital heart defects (CHD) refers to a group of conditions occurring when one or more structures of the heart does not form correctly. CHD is the most common type of birth defect. Most of the time the heart defect is the only issue but sometimes the heart defect can be part of a *genetic syndrome* that affects multiple body systems.

Congenital heart *disease* and congenital heart *defects* are often used interchangeably. There are several different types of CHD and CHD can range from mild to severe. Some may demonstrate life-threatening symptoms at birth and require immediate surgery. Others may not be diagnosed until teenage or adult years. Learn about the specific condition and needs of each unique child.

Common Features of CHD:

- Smaller stature than classmates
- Shortness of breath after exercise and decreased stamina
- Susceptibility to lung infections, e.g. pneumonia
- Bluish skin due to low oxygen levels
- Learning problems or developmental delays
- **Children With CHD May Require**
    - Supplemental oxygen
    - Limitations on activity
    - Extra hydration and/or protection from overheating
    - Extra time to travel between classes
    - Extra access to a bathroom if taking a diuretic medication

In Depth

Medical and Dietary Considerations

What you need to know

There are many types of Congenital Heart Disease (CHD) each with its own specific symptoms and medical concerns. Make sure that you understand the specific type of CHD affecting the child and familiarize yourself with their challenges and resources. The severity of CHD varies widely among individuals. Therefore, it is important to ask the parents about the severity of the CHD in *their* child and read all pertinent medical information.

School-age children with CHD may have multiple doctor and specialist visits to monitor medical conditions. They often have limited exercise capacity and may be more susceptible to lung infections. Depending on their condition, they may be on medications or use oxygen. In general, no special diet is required for individuals with a CHD although a well-balanced diet is important. Extra water to keep hydrated may be important. Some children with CHD may have specific dietary concerns, e.g., restricting fat or sodium. Follow the recommendations from the child's medical home.

What you can do

- Encourage at least yearly check-up in the child's Medical Home. Get copies of any updated recommendations.
- Review plans at least annually
    - Be aware of any activity restrictions
    - Be aware of any medication including possible side effects
    - Be aware of any other issues to watch for and recommended actions
- Consider automated external defibrillators (AED) on site.
    - School personnel will need to be trained in their use.
- Arrange CPR training for staff
- Permit students to visit the nurse for needed medications
- Be aware of any changes in behavior or mood that seem out of line with the norm and notify the parents.
- Be aware of any academic changes. Contact parents when any differences are noticed.

Education Supports

It is important to have high learning expectations for children with CHD utilizing their strengths and interests as a foundation. Encourage use of the core educational curriculum and modify it to meet the child's individual needs.

What you need to know

Individuals with a complex CHD may be at increased risk for neurodevelopmental issues, developmental disabilities, delays in cognitive functions of the brain and in the brain's relationship with emotion, behavior, and motor skills. However, not all children with CHD have neurodevelopmental problems and those who do usually don't have severe delays.

The following may be more common in individuals with a CHD
- ADHD
- Mild cognitive impairment
- Impaired social interaction
- Impairments in core communication skills including speech and language and motor skills
- Deficits in attention

What you can do

Educational Supports:

- Manage educational issues as you would for other children
- Speech and language therapy and supports that are individualized to the child may be helpful
- Support social skills development
- Misconceptions of abilities can cause insecurity and anxiety in social situations
- Make sure teaching strategies being used are appropriate for children who are already *socially engaged.*
- Provide social cues and coaching.

Physical Therapy:

- Develop gross motor abilities
- Improve strength

Behavioral and Sensory Support

What you need to know

Individuals may have temporary behavior changes after surgery. Counseling may be appropriate. In middle school, children with CHDs may become concerned about being different. This may create anxiety.

What you can do

- Encourage discussions about differences and acceptance of differences within classroom
- If activity limitations inhibit the child's ability to participate in many of the activities of their peers
    - encourage participation in coaching or team management

Created by NERGN with funding from HRSA grant UH7MC30778. Revised 5/2024

    - provide more academic and artistic group activities that can foster similar skills and social opportunities
- Some individuals may need additional time to get to class
    - Limit unnecessary movement between classes

Physical Activity, Trips, Events

What you need to know

It is important to discuss the nature of the student's heart condition and implications for school activities. The child's physicians will determine the student's permitted activity levels.

Physical Education:

- It is important for individuals with CHDs to have physical activity to optimize physical and mental health.
- Certain CHDs and syndromes (e.g., Marfan syndrome).will have very specific recommendations regarding physical exercise and restrictions

Field Trips:

- Children with CHD do not typically have difficulties on field trips.
    - Exceptions may be on field trips that have a lot of physical activity, if the child has restrictions.

What you can do

- Encourage academic and artistic activities if physical activities are more restricted
- Allow child to help with coaching or team management if there are restrictions.
- Consider 504 for physical activity modifications if appropriate
- Instruct in self-monitoring technique.
    - Provide opportunities for practice of self-monitoring
    - Instruct in relaxation techniques, safety, and breathing
- Allow additional time to get to class if needed
    - Limit extra movement between classes if necessary
- Make sure the child has extra water
- Make sure an automated external defibrillator (AED) is available if the condition warrants one.

School Absences and Fatigue

What you need to know

Children with CHD may have more absences than typical due to surgery, illness and/or medical appointments. Children with CHDs may be tired in general or fatigue easily during the day.

What you can do

- Help to make transitions in and out of school as seamless as possible
- Allow extra time for assignments and/or provide make up work as needed.
- Make accommodations for resting or taking break
- Have peers/teachers share class notes
- Monitor work so that it is challenging, but there are attainable and realistic goals
- Plan for absences and consider tutoring
- Communicate with parents to meet these challenges
- Provide rest breaks, extra water and monitor them in hot conditions

Emergency Planning

Consult with child's medical home. Develop an emergency plan, if necessary, depending on the needs of individual children. Consider the following:

- Ensure medications are available and not expired.
- Have extra water available
- Have AEDs available
    - Ensure batteries are checked on regular basis
    - Ensure staff know how to use
- Have staff trained in CPR

Resources

Medline Plus

MedlinePlus is an online health information resource for patients and their families and friends. It is a service of the National Library of Medicine. This link will provide a good medical overview of the condition without being too technical.
https://medlineplus.gov/congenitalheartdefects.html

American Heart Association

The American Heart Association provides information and educate about heart disease, including congenital heart defects.
https://www.heart.org/en/health-topics/congenital-heart-defects

CDC

The CDC has a comprehensive page about CHD with information about the different types of defects and other helpful resources.
https://www.cdc.gov/heart-defects/about/index.html#cdc_disease_basics_types-types

Info for School Nurse and Primary Care Staff

Congenital Heart Disease can range in complexity and severity. It will be best managed by good collaboration between the school nursing staff and primary care staff as part of the student's team. Work with the parents to get signed releases to share information at the school nurse's office and the primary care office.

Sometimes concerns by primary care staff about violating HIPAA regulations can hamper care by limiting access to necessary medical information. Please note that if care is intended to be delivered by school staff, clarifying medical orders or medication instructions represents continuation of medical care and is not a violation of HIPAA. To avoid any issues like this, remind the parents to sign a release of information form at the primary care office. The school nurse should keep a copy of that release in the student's file, if possible, to facilitate sharing of information in the event that there is difficulty obtaining needed information.