Cardiac Neurodevelopmental Outcome (CANDO) Program

Children and Adolescents with Congenital Heart Disease (CHD): Information for School Teams

This information is designed to help teachers, nurses, school counselors, and other school staff members to better understand congenital heart disease (CHD) and its impact on a child’s academic and behavioral growth.

CHD is a problem with the heart's structure and function that is present before birth. CHD can describe a number of different problems affecting the heart, and is the most common type of birth defect. It is important to know that CHD are related to changes in brain development, as well. Changes in blood flow related to CHD can have a direct impact on a child’s brain development.

Children with congenital heart disease can attend school and participate fully, but some children with CHD may have delays in development, learning disabilities or special education needs. Most school districts, with the aid of their school teams, can assist in supporting the needs of children with CHD in the school environment.

The school team can coordinate a range of support services for the family and the child with CHD. Contact the parents/guardians after learning of the diagnoses, and if possible, meet with them in person. Inform appropriate school staff of the child’s disease and provide the necessary supports to ensure the child is successful in school.
What does the child’s teacher need to know?
It is important that teachers know the nature of a student’s heart condition and the implications it has for school activities. For example, if there are only 5 minutes between classes but a child with a heart condition needs 10 minutes to travel from one class to another, arrangements should be made to give the child extra time to get to class and not be penalized for taking a few extra minutes. Parents/guardians and physicians can provide information about the child’s health, permitted activity level, medications, and future treatment.

How will the child perform at school?
Some children with CHD do not require any special care when they attend school. There is a substantially increased risk, however, for having needs around learning, attention, and social-emotional development. A child with CHD may:

- Experience difficulty in the areas of reading, mathematics, and language arts.
- Be inattentive or hyperactive in the classroom.
- Have executive skills weaknesses, such as problems with organization, working memory (e.g., short term memory) or self-monitoring.
- Have difficulties with higher order/pragmatic language or social skills.
- Have more difficulty with fine motor skills, visual-motor skills or processing visual-spatial information.

In addition, some children may experience complications related to surgeries or other interventions, such as strokes, that will lead to changes in neurological status. It is important for parents/guardians and teachers to communicate regularly regarding any changes in a child’s functioning, so that their supports and services can be modified accordingly.

What physical symptoms might the teacher observe in a student with CHD?
Children with CHD experience a wide variety of symptoms depending on the nature of their defect and status of their repair. They can range from being entirely asymptomatic (no symptoms) to being very easily fatigued and cyanotic (a blueish tint to the skin). It is very important to confirm with the parent/guardian if the child has a tendency to experience any symptoms.

What is the student’s permitted activity level?
Permitted activity levels are determined by the child’s health care team. In general, activity restrictions are graded in the following manner:
• **Full:** The child is allowed to exercise at will and participate fully in all sports.
• **No competitive sports:** The child is allowed to exercise but is not allowed to participate in races, organized games, or team sports.
• **Restricted:** Please obtain specific guidelines from your child’s doctor.

If you have questions about any activity restrictions, please contact the parent/guardian.

**Does the child take medications at school?**
Medication is usually taken at home. In cases where a child needs to take some medication while at school, arrangements will be made with the school nurse or school system employees. The teacher should be kept informed of the medications the child is taking and of their specific purpose.

**Should the child’s teacher be informed about medical plans?**
Parents/guardians must authorize the release of medical information. Continuous contact with the parent/guardian will keep the teacher and school team informed about plans, if any, for the child’s future treatment or hospitalization. This information can help the teacher identify and respond to the child’s needs and concerns. The possibility of hospitalization or surgery may create anxiety, which sometimes results in changes in behavior and performance at school.

**What should the teacher do if the child is having surgery?**
To help the child prepare for surgery, the parent/guardian will discuss the date of surgery with the school team, the reason for it, the proposed length of hospitalization, and the time needed to recover before the child can return to school. Parents/guardians will also determine whether it is alright for the teacher to discuss the surgery with the child’s classmates. If the child is going to be in the hospital for an extended amount of time, a home and hospital teacher may support his or her educational needs. A child in the hospital can benefit from contact with his or her classmates. Speak to your student’s parent/guardian about ways the child’s classmates can get involved. It can take the form of get-well cards.
Will the teacher observe some behavioral changes?
The teacher may encounter some behavioral changes when the child returns to school. You may see an improvement in the energy or activity level of a child after surgery. It is important for you to discuss any behavioral changes with the parent/guardian.

How can the school team support the child?
Students with a congenital heart condition need your support to develop to their full academic potential. If a student has any special needs arising from a cardiac problem, he or she should be referred to the Individualized Educational Program (IEP) Team for review.

Educational Planning

- Ensure prompt identification of learning, attentional, and social challenges.
- Determine if a 504 Plan or Individualized Educational Program (IEP) may be needed.
- Determine if Home and Hospital Instruction (HHI) may be necessary around the time of surgical interventions and/or hospitalizations.
- Provide modified assignments and/or additional time for class work, homework, quizzes, and tests when a student is out of school due to hospitalizations.
- Develop a plan with parents/guardians to make sure that assignments and homework are obtained in a timely manner when the child misses school.

This document includes some of the most common issues and needs of children with congenital heart disease (CHD), however, each child is different and some children may require additional accommodations. We hope this information is helpful in your understanding of CHD, caring for a child with CHD and its complications.

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