

Congenital Heart Defects At a Glance

Congenital heart defects (CHDs) refers to a group of conditions causing one or more abnormalities in the structure of the heart. CHDs may be isolated (not appear with any other conditions) or occur as part of a genetic condition.

About 8 out of every 1,000 newborns have a CHD. These CHDs can range from mild to severe. Some CHDs may cause serious symptoms at birth and require immediate surgery. Other heart defects may not be diagnosed until teenage or adult years.

The term critical congenital heart disease or CCHD is a term used to mean any heart defect that is present at birth that causes less oxygen in the blood. Congenital heart disease and congenital heart defects are often used interchangeably.

Things to think about

1. Medical and Dietary Needs

What you need to know

- 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. Children with CHD may have special dietary concerns (i.e. high fat or low sodium) especially when young.
- The severity of CHDs varies widely between individuals. Therefore, it is important to ask the parents about the severity of the CHD in their child and read all pertinent medical information.
- 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.
- School age children with CHD may have multiple doctors and specialist visits to monitor medical conditions.
- Be aware, or ask parents, if the child has a medical alert bracelet.

Physical characteristics and/or symptoms:

Not all people with Congenital Heart Defects have all of these characteristics.

Common Types of Heart Defects

The American Heart Association website has information about common types of heart defects (below), and how they can offer support:

- Aortic Valve Stenosis (AVS)
- Atrial Septal Defect (ASD)
- Cardiomyopathy
- Coarctation of the Aorta (CoA)
- Complete Atrioventricular Canal defect (CAVC)
- d-Transposition of the Great Arteries
- Ebstein's Anomaly
- Hypoplastic Left Heart Syndrome
- I-Transposition of the Great Arteries
- Patent Ductus Arteriosus (PDA)
- Pulmonary Atresia
- Pulmonary Hypertension
- Pulmonary Valve Stenosis
- Single Ventricle Defects
- Tetralogy of Fallot
- Total Anomalous Pulmonary Venous Connection (TAPVC)
- Tricuspid Atresia
- Truncus Arteriosus
- Ventricular Septal Defect (VSD)

http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/Common-Types-of-Heart-Defects_UCM_307017_Article.jsp#.VorYR_krK71

http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/Congenital-Heart-Defects_UCM_001090_SubHomePage.jsp

Children with a CHD may:

- Be shorter or lighter than classmates

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- Tire easily and be short of breath after exercise
- Have increased susceptibility to chest infections and/or respiratory infections (i.e. pneumonia)
- Have activity restrictions
- Need to carry a water bottle to stay hydrated and/or stay indoors on hot days
- Need extra time to travel between classes
- Need access to a bathroom if taking a diuretic medication
- Have bluish skin color due to low oxygen levels
- Need to use supplemental oxygen
- Have learning problems or developmental delays

Syndromes on GEMSS that may include a heart defect

More information about the following genetic conditions which may have congenital heart defects as a characteristic finding can be found on the GEMSS website (<http://www.gemssforschools.org/>):

- 22q deletion syndrome
- Cornelia de Lange
- Down syndrome
- Fetal alcohol syndrome
- Kabuki syndrome
- Marfan syndrome
- Noonan syndrome
- Tuberous sclerosis
- Turner syndrome
- VLCAD
- Williams syndrome

What you can do

- Be aware of any restrictions that might be placed on activities.
- Automated external defibrillators (AED) may be need on site.
 - School personnel will need to be need trained in use.
- CPR training for staff
- Students may need to visit the nurse to take medications during school

- Be aware of any medication side effects
- A yearly check-up and studies as needed should occur in the child's Medical Home.
- Be aware of any changes in behavior or mood that seem out of line with the norm and notify the parents.
- It is important to be aware of any academic changes. Contact parents when any differences are noticed.

2. Education Supports

What you need to know

It is important to have HIGH LEARNING EXPECTATIONS for children who have Congenital Heart Defects. Encourage use of the core educational curriculum and modify it in order to meeting the individual needs of the child.

Although the reasons are not completely understood at this time, it does appear that 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
- Speech and language and motor skills
- Deficits in attention

Neurodevelopmental disorders associated with *more complex* CHDs may be caused by:

- Genetic syndromes that include a congenital heart defect
- Medical and surgical treatment required for the CHD

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- Poor circulation
- Living with day-to-day stress of having a chronic or serious heart condition
- Defects that are more serious
 - For example, some have required open-heart surgery as an infant or have caused the child to appear bluish due to poor circulation.

Studies have shown that other risk factors for developmental disorders include having a combination of both congenital heart disease and one of the following:

- Premature birth
- Developmental delays as a baby
- Suspected genetic abnormality or syndrome
- A history of mechanical support to help the heart
- Heart transplantation
- A history of cardiopulmonary resuscitation (CPR)
- Prolonged hospitalization during the child's heart care
- Seizures related to heart surgery
- Brain abnormalities seen in brain images

What you can do

Educational supports:

- Treat the 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

3. Behavioral and Sensory Support

What you need to know

Individuals may have behavior changes after surgery.

- These are usually temporary changes.
- Counseling maybe 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

4. Physical Activity, Trips, Events

What you need to know

Physical education:

- Many children with CHDs can fully participate in most physical and extra-curricular activities.
- It is important for individuals with CHDs to have an opportunity for physical activity to optimize physical and mental health.
- Certain CHDs and syndromes will have very specific recommendations regarding physical exercise and restrictions (i.e. Marfan syndrome).
 - Exercise is important and should be encouraged, especially those exercises that build muscle mass and motor skills.
 - May be able to exercise but not participate in contact sports.
- If you live in New England (USA) and qualify, Northeast Passage offers Therapeutic Recreation and Adaptive Sports programming (www.nepassage.org).

Field trips:

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

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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
- Some individuals may need additional time to get to class
 - 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.

5. School Absences and Fatigue

What you need to know

Absences:

- Children with CHD may be absent due to surgery, illness and/or medical appointment.

Fatigue:

- Children with CHDs maybe tired and require rest opportunities or breaks in 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 share class notes
- Monitor work so that it is challenging, but there are attainable and realistic goals
- Plan for absences and consider tutoring
- Communication with parents is important to meet these challenges
- Provide rest breaks, extra water and monitor them in not conditions

6. Emergency Planning

What you need to know

- Develop an emergency plan if necessary, depending on the needs of individual children.
- Have AEDs available
- Have extra water

7. Resources

My American Heart

<http://my.americanheart.org>

This organization's goal is to educate and support for individuals affected by congenital heart defects or heart disease.

American Heart Association

<https://www.heart.org/en/health-topics/congenital-heart-defects/>

The American Heart Association provides information and educate about heart disease, including congenital heart defects.

Medline Plus

<https://medlineplus.gov/genetics/condition/critical-congenital-heart-disease/>

This information, from the U.S. National Library of Medicine, is about critical congenital defects present at birth. It also has general information about genetics and heart defects.