



Ensuring a Good Learning Environment:

**A Cardiomyopathy Guide
for School Personnel**



Pediatric Cardiomyopathy

This guidebook is written for teachers and school personnel who may be responsible for the education or care of a child with pediatric cardiomyopathy. Cardiomyopathy presents unique challenges to children, families and caregivers, but with education and awareness, these challenges can be effectively addressed. Most children with this chronic heart disease are able to successfully attend school with their peers. Your familiarity with the disease and its required accommodations will help the child (or children) with pediatric cardiomyopathy in your school have a safe, productive and enjoyable school year.

This guide provides basic information about pediatric cardiomyopathy, including the medical, social and emotional issues associated with the disease.

It provides suggestions for how to best meet the child's needs, including:

- preventing and responding to emergencies
- promoting the best learning environment
- ensuring adherence to medically related needs
- promoting social growth and development for the child with pediatric cardiomyopathy, as well as his or her peers

With your help, the child with cardiomyopathy will grow in confidence and security, and will be able to perform to his or her maximum potential.

Pediatric Cardiomyopathy Defined

Pediatric cardiomyopathy is a chronic heart disease that affects the pumping action of the heart. Depending on the form of cardiomyopathy, the heart muscle (myocardium) becomes enlarged, thickened and/or stiffened, which restricts its ability to contract and pump blood effectively. In addition, the heart may beat too fast, too slowly or unevenly.

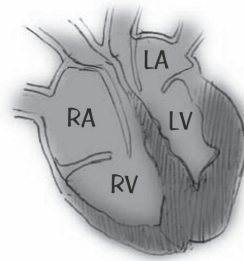
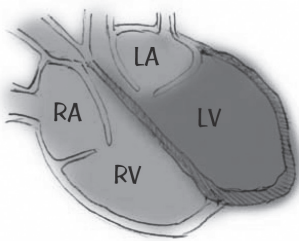
Four Main Types of Cardiomyopathy

- Dilated cardiomyopathy (DCM)
- Hypertrophic cardiomyopathy (HCM)
- Restrictive cardiomyopathy (RCM)
- Arrhythmogenic right ventricular cardiomyopathy (ARVC)

In addition, a fifth form is increasingly becoming recognized: left ventricular non-compaction cardiomyopathy (LVNC).

Forms of Cardiomyopathy

The forms vary according to the location of tissue damage and the underlying disease process, but all types of cardiomyopathy can weaken the heart and cause it to work harder than normal. In some cases, the heart may become compromised and unable to pump enough blood to meet the body's needs. At an advanced stage of the disease, fluid may build up in the lungs and other organs when the child is in congestive heart failure.

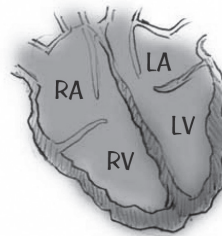
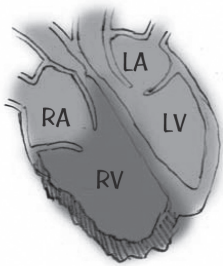


DCM = dilated cardiomyopathy

The left ventricle (LV) is bigger and weaker than it should be. This makes it hard for the heart to squeeze properly.

HCM = hypertrophic cardiomyopathy

The heart muscle becomes thick and cannot relax properly.



ARVC or ARVD = arrhythmogenic right ventricular cardiomyopathy or dysplasia

The healthy muscle of the right ventricle (RV) gets replaced with fat and scar tissue. The RV can get bigger and have trouble squeezing and relaxing.

RCM = restrictive cardiomyopathy

The wall muscle of the heart becomes stiff. Even though it can squeeze and relax, it becomes harder to fill the heart with blood.

RA = Right Atrium
RV = Right Ventricle
LA = Left Atrium
LV = Left Ventricle

Q&A

Q: Who is affected?

A: Cardiomyopathy is estimated to affect over 30,000 children in the U.S., a number comparable to those affected by cystic fibrosis. It affects children of both genders and every race, nationality and socio-economic class. It is believed that for every child diagnosed with cardiomyopathy, there is at least one other child with the disease who remains undiagnosed.

Q: What causes pediatric cardiomyopathy?

A: Pediatric cardiomyopathy is a poorly understood disease, and the cause remains unknown, or idiopathic, in two-thirds of patients. Of those with a known cause, the majority of cases have a genetic origin. The disease may also be acquired, with the most common cause being myocarditis, a viral infection that causes inflammation of the heart muscle. Cardiomyopathy may develop in response to other medical problems such as Noonan syndrome, inborn errors of metabolism, muscular dystrophies and cancer therapy, to name a few.

Q: How serious is pediatric cardiomyopathy?

A: Pediatric cardiomyopathy is a chronic disease that varies widely in severity. Some children have mild or no symptoms and can lead normal lives with the help of medications. Others have more severe symptoms that require heart surgery (myectomy), a mechanical heart (ventricular assist device) resulting from heart failure, or a heart transplant. Some children with cardiomyopathy are at a greater risk for sudden cardiac arrest.

Q: How is pediatric cardiomyopathy treated?

A: There is no cure for cardiomyopathy, although treatments can help to control symptoms, slow its progression and prevent complications.

Drug therapy is used to improve the heart's function and to control symptoms related to heart failure or heart obstruction. Drug therapy can also prevent complications such as blood clots and abnormal heart rhythms.

Children who have an abnormal heart rhythm may need the assistance of a pacemaker, an automatic implantable cardioverter defibrillator (AICD) or a biventricular pacemaker.

Some children with hypertrophic cardiomyopathy may require open heart surgery, called septal myectomy, to reduce severe symptoms.

A heart transplant may be needed if a child progresses to end-stage heart failure and can no longer be helped by medications and surgery. Cardiomyopathy is the leading indication for heart transplantation in children; 20 percent of those with symptoms require a transplant within one year of diagnosis.

Challenges and Concerns

Quick Facts about Pediatric Cardiomyopathy

- ✓ Cardiomyopathy can be either inherited or acquired during childhood.
- ✓ There is no cure for cardiomyopathy, although treatments can help to control symptoms and slow the progression of the disease.
- ✓ Children with cardiomyopathy can develop signs of heart failure quickly and without warning.
- ✓ Some children with the disease are at risk for sudden cardiac death.
- ✓ With appropriate treatment, activity restrictions, and other accommodations, children with cardiomyopathy can participate in all learning and social experiences in school.

Medical Concerns Associated with Pediatric Cardiomyopathy

There are many medical issues associated with cardiomyopathy, but the greatest concern is the risk of early and/or sudden death. The section on “Preparation for Emergency” (page 14) details symptoms to watch for and steps to take if an emergency arises.

Helping a Child with Medical Concerns

In the absence of a cardiac emergency, a number of medical challenges still need to be addressed on a daily basis. Proactively addressing these concerns with school-approved accommodations and modifications will help to ensure the health and well-being of children with cardiomyopathy in the school setting. The diagnosed child may have one, some or all of the concerns shown in the chart to the right.

Common Medical Concerns

Suggested School Modifications & Accommodations

Medications needed during school hours

- Understand intake schedule and administration procedure.
- Provide hall passes and allow time for scheduled nursing visits.

Side effects from medication such as diminished concentration or increased need to use the restroom

- Understand the child's health plan, including potential effects of medications and how they may affect school performance.
- Schedule extra time for certain tests.
- Allow restroom privileges as needed.

Physical activity restrictions due to the risk of sudden cardiac arrest

- Modify physical education class as recommended by the child's physician.
- Work with the child to select alternative activities.

Dietary monitoring, increased food and fluid intake

- Allow child to have water or snacks in the classroom if recommended.
- Work with school on meal plans and inform lunch supervisor of any special food needs.

Fatigue due to medications or diagnosis

- Allow two sets of textbooks (one for home and one for classrooms) if needed.
- Permit access to elevators if stairs are problematic.
- Schedule classes closer together or allow extra time to travel within buildings.
- Schedule breaks for the child during the day if needed.
- Arrange for a peer buddy to accompany the child and help carry books if needed.

Frequent absences due to illness, hospital treatments and doctor visits

- Meet with the parents to determine ways to meet the academic needs of the student.
- Allow the child to reschedule tests or make up assignments without penalty.
- Allow time to make up work while recovering from illness or surgery.
- Make arrangements for home education if extended absences occur.
- Have a buddy provide copies of class notes if absent due to medical reasons.

Possibility of symptoms occurring at any time

- If a child develops symptoms, accompany the child to the nurse or office for evaluation and notify the parent or guardian.
- Special events, extracurricular activities and field trips may require advance planning.

Use of a pacemaker or an implantable cardioverter defibrillator (ICD)

- Avoid contact sports that could cause impact to the device site.
- Avoid strong electrical or magnetic fields, including strong magnets, security wands, high power lines, anti-theft devices at libraries and battery-powered cordless power tools.

Greater intolerance to illnesses

- Inform nurse and parents if the child develops signs of an illness.
- Inform parents of any school outbreaks of communicable illnesses such as chicken pox or influenza.
- Promote frequent hand washing or use of hand sanitizing gel.

Challenges and Concerns

Social and Emotional Concerns Associated with Pediatric Cardiomyopathy

Children with cardiomyopathy may feel a range of emotions about having a chronic health condition. Depending on their age and when they were diagnosed, they may be accepting of their condition and open to discussing it, or they may feel resentful, embarrassed or in denial.

Common social and emotional concerns include:

- Physical differences, including small stature, which may impact self-esteem or confidence
- Medication side effects, such as weight gain and increased need to use the bathroom, which may cause embarrassment
- Bullying by classmates
- Depression or anger due to social isolation caused by activity restrictions
- Anxiety or fear of death from being very ill, surviving a cardiac arrest or having their pacemaker/defibrillator activated in front of peers

Children's reactions to having cardiomyopathy may fluctuate at times, and they may have difficulty recognizing or expressing their emotions. If concerns arise about the way a child is coping with his or her diagnosis, consult with the school counselor and child's parents.

Helping a Child with Social and Emotional Concerns

In most cases, children do not want to be singled out or made to feel different than their peers. Exclusion from normal activities can lead to social stigmatization and loss of self-esteem in the child. Successful peer relationships will improve the child's quality of life and enhance self-esteem.

The following suggestions will help to make the child as comfortable as possible, while integrating him or her as fully as possible into normal daily activities.

Common Social & Emotional Concerns	Suggested School Modifications & Accommodations
<p>Loss of identity and self-esteem issues due to physical activity restrictions:</p> <p>The inability to play sports can lead to emotional issues, especially if the activity that needs to be given up is closely linked to a child's identity.</p>	<ul style="list-style-type: none">• Help the child develop new sports interests (e.g. golf) or involve them with team sports in non-physical ways, such as by becoming a manager, scorekeeper or assistant.• Introduce activities that allow children to mentor or work with younger children to provide the experience of being a "helper" rather than one always being "helped."• Help them explore outlets for self-expression other than sports, such as art, music, theater, film production, working with animals (e.g. dog training) and other activities.• Consider introducing computer-oriented activities such as graphic design, chess, word games or web programming.
<p>Social isolation related to physical activity restrictions:</p> <p>Children may feel "left out" and become frustrated when they can no longer engage in certain activities with their friends.</p>	<ul style="list-style-type: none">• Encourage more social interactions and participation in extracurricular group activities.• Assign a peer "buddy" to help manage books, lunch trays or accompany a child through the halls. A buddy can also watch out for signs of a medical emergency, help protect from bullying, and stay inside to play with the child if they can not participate in recess due to extreme weather.
<p>Communicating with other students:</p> <p>Classmates may be curious about the child's condition. Teachers may be in the position of fielding questions from children and need to know how to respond.</p>	<ul style="list-style-type: none">• Discuss with the parents and the child what information related to physical differences, medical needs or accommodations they are comfortable sharing with the class.• Develop lesson plans to help explain cardiomyopathy to the class.

Physical Activity Restrictions

In some children with cardiomyopathy, physical activity restrictions may be recommended by the cardiologist. The degree and type of activity restriction will vary depending on the type of cardiomyopathy, clinical severity, medical treatment and family history.

An important goal, even in the presence of physical activity restrictions, is for the child to participate in as many normal daily activities as possible to maintain both physical and mental health. The guidelines for physical activity restrictions should be set by the child's physician. Based on these guidelines, the gym instructor and teacher should design a physical activity program based on the child's needs, abilities and limitations.

When designing an individualized exercise program, the gym instructor should involve the child and parent in selecting safe activities that allow the child to enjoy physical activities with their classmates. Modifications should address issues of intensity, endurance and fatigue.

General Guidelines for Activity Modifications

- Exercise or recreational sports should not be pushed to the point of exhaustion.
- Permit participation at child's own rate, with freedom to rest as necessary.
- Instruct the child in self-monitoring techniques so he or she understands how to keep from becoming overly tired.
- Provide adequate time for gradual warm-up and cool-down and teach relaxation techniques, safety and proper breathing mechanics.
- Monitor the child's level of exertion more closely under extreme weather conditions.
- Ensure that the child is well hydrated during prolonged exercising or exercising in extreme heat.
- During exertion, maintain a heart rate in an acceptable range as recommended by the child's physician.

Important Points to Remember

Children with chronic illnesses face many concerns. Often the social and emotional issues related to cardiomyopathy are overlooked when planning for their accommodations.

- ✓ If the child is in denial or tries to hide the condition from his or her peers, this may lead to non-compliance with medications or activity restrictions.
- ✓ Children with cardiomyopathy may experience anxiety and depression related to their condition.
- ✓ They may be afraid of their defibrillator going off in front of their peers or of having a cardiac arrest.
- ✓ Children may feel socially isolated because of their activity restrictions.

The School Setting: Accommodations for Pediatric Cardiomyopathy

As discussed, a child's medical and social concerns require specific accommodations and modifications within the school setting. Requirements will depend on the diagnosis and severity of the child's disease. Health and education plans developed by the parents and school personnel will describe the child's condition and necessary accommodations and modifications.

School personnel should understand the social, emotional and medical factors affecting a child with cardiomyopathy and be actively involved in working with the parent and child to address them.

Requirements of School Personnel

According to federal law, school districts must provide a safe and supportive educational environment for students with chronic illnesses and ensure that such students have the same educational opportunities as do other students.

The key laws include Section 504 of the Rehabilitation Act of 1973, Individuals with Disabilities Education Act (IDEA), Americans with Disabilities Act of 1990 (ADA), and the Family Educational Rights and Privacy Act (FERPA).

A collaborative team approach is best for managing the unique needs of a child with cardiomyopathy, including preventing and responding to emergencies, encouraging an optimal learning environment, and promoting academic and social development.

School Responsibilities

- Identify students with chronic health conditions.
- Review their health records as submitted by families and doctors.
- Meet with the child's family to discuss health accommodations and educational needs, as described in the child's health, emergency and education plan.
- Provide nondiscriminatory opportunities to students with disabilities.
- Develop protocols for school staff for coordinating the health and educational needs of the child.
- Implement strategies to ensure the student's safety and ability to participate in school activities, after school programs, offsite events, extracurricular activities and field trips.
- Ensure that the student receives medications as directed.
- Schedule staff training to handle health needs and emergency situations.
- Develop a protocol to maintain records and communicate information to staff as needed, while protecting confidentiality.

Advance Planning: Educational, Health and Emergency Plans

There are usually three plans involved – a health plan, emergency plan and education plan – which provide a platform for essential communication between the parents of a child with cardiomyopathy and his or her school. Parents will work with the school to prepare these plans and discuss the proposed modifications and accommodations with the school team during a planning meeting before school starts or upon diagnosis of their child. All designated school personnel should be familiar with these plans and have access to them throughout the school year.

Health Plan

A medical management or individual health plan is usually developed by the parent and child's physician to address the health needs of the student. Although this is not required by law, a written plan of care helps the school team to understand the medical needs of the child with cardiomyopathy. The plan describes the child's medical, social and academic situation, care management needs, and includes activity restrictions and emergency contact information. The health plan is usually kept by the school nurse.

Emergency Plan

This is a step-by-step plan with easy-to-read directions about how to handle emergency situations such as sudden cardiac arrest. The emergency care plan will be developed with input from the child's physician and will include information about the child's medical condition and treatment, warning signs requiring medical attention, appropriate interventions and emergency contacts.

Education Plan

Depending on the child's condition, he or she may require a range of school modifications or accommodations to help function at his or her maximum potential. There are two primary education plans used by schools and parents to define the special needs of children with disabilities or chronic illness — the Individualized Education Plan (IEP) and Section 504 plan. Determining which plan to use depends on the severity of a child's condition, what services may be needed and how individual states interpret the laws. While children with cardiomyopathy are more likely to require a Section 504 plan, some children with cardiomyopathy related to other medical problems may have additional educational needs that render them eligible for an Individualized Education Plan.

An emergency plan must be available to all school staff, including substitute personnel, who have daily contact with the affected child.

The School Team: **Communication and Collaboration**

The guidelines in this booklet provide a suggested approach toward developing optimal collaboration between the family and school team.

At the beginning of the year (or upon diagnosis, if it occurs mid-year), parents may request a meeting with the principal and other appropriate school personnel. The principal can assemble the team, which may include the child's teacher, nurse and other appropriate staff such as the gym instructor, school counselor and special education coordinator. During this meeting, parents provide the school with information about the child's health and medical needs, and then work together with the team to develop the necessary plans and appoint a plan coordinator. If it appears that the child may be eligible for an Individualized Education Plan (IEP), further evaluation may need to be arranged.

The goal is to establish an ongoing relationship between the school system and family to ensure that the rights and needs of the student are being met. School personnel should feel free to contact the parents in order to better understand and utilize the health, emergency and education plans. If consent has been obtained from the parent or guardian, it may also be helpful for school personnel to contact the child's physician for more information.

It is essential for the school to maintain regular communication with parents and to initiate meetings if a change in the child's health or well-being occurs.

Development of Protocols

Parents and the school team, in concert with the district, will need to establish clear, thorough protocols to do the following:

- ✓ Designate who will have access to the child's information.
- ✓ Establish emergency response protocols, including identification of first responders, alternates and reliable chains of communication.
- ✓ Create off-site emergency protocols.
- ✓ Schedule staff training in CPR and AED response.
- ✓ Notify parents in advance of changes in school schedule, such as class parties, field trips and other events.
- ✓ Determine how to respect the child's and family's wishes for privacy, while ensuring the child's safety and adherence to medically necessary instructions.
- ✓ Communicate about the child's diagnosis and needs with regular and substitute personnel, including bus drivers, teachers, cafeteria supervisors and librarians.
- ✓ Periodically review the child's health plan and other pertinent information with the child's parents.
- ✓ Monitor compliance with these plans and schedule follow-up meetings.
- ✓ Ensure that school personnel know their roles in carrying out the child's plans, how their roles relate to each other, and when and where to seek help.

Warning Signs for Cardiomyopathy

If the following warning signs occur, the child may require immediate medical attention:

- ✓ Dizziness or fainting
- ✓ Shortness of breath or fast breathing out of proportion to the level of physical activity
- ✓ Rapid or irregular heartbeat
- ✓ Numbness or tingling in the hands or feet
- ✓ Vomiting or abdominal pain
- ✓ Persistent chest pain, pressure or discomfort
- ✓ Trembling
- ✓ Disorientation, alteration in speech, hearing, vision, coordination or balance

Preparation for Emergency

School personnel should be aware that a child with cardiomyopathy may develop symptoms that signal the need for immediate medical attention. Symptoms related to physical exertion may indicate that the heart is unable to keep up with the extra demands required by the activity. In this case, the child should stop the physical activity and be taken to a quiet place to rest and be observed. A child exhibiting symptoms should never be left alone.

An emergency care plan, with contact information for notifying the child's family and physician, should be easily accessible in case of an emergency. A photo card could be kept in the school office and placed on the teacher's desk in each child's classroom for review by any substitute teacher. An information card could be provided to the bus driver or school transportation department.

School personnel should notify the local emergency medical services (EMS) of the child's condition in advance, so that they will be fully prepared if an emergency occurs. In the event of an emergency, other students should be removed from the area.

CPR and AED Training

At all times, school personnel must be available who are trained in cardiopulmonary resuscitation (CPR) and the use of an automatic external defibrillator (AED).

If it is not possible for every staff member to receive training, every person who is in charge of the child during any point in the day should be trained. This includes not only the child's primary teacher but other teachers who supervise the child for shorter periods, including the art teacher, music teacher, librarian, lunch supervisor, playground supervisor, the nurse, counselor, etc. Alternatively, multiple school personnel should be trained in these measures so that at least one trained staff member will be present in the event of an emergency.

An AED should be accessible at all times and located in such an area that it can be transported anywhere in the school within 1–2 minutes. If necessary, multiple AEDs should be placed at key locations throughout the school.

Training in CPR and the use of AEDs using pediatric pads should be provided before the beginning of the school year, when a student is diagnosed or when a student with cardiomyopathy is enrolled in the school. Refresher sessions should be offered each year to keep staff updated. The AED should also be checked periodically for battery status.

If suggested by the child's physician, an AED should be brought on field trips.

Additional Resources

Resources on managing school-age children with chronic health conditions

- American School Health Association (www.ashaweb.org)
- Individuals with Disabilities Education Act (<http://idea.ed.gov>)
- National Institutes of Health: Students with Chronic Illnesses – Guidance for Families, Schools and Students (www.nhlbi.nih.gov/health/public/lung/asthma/guidfam.pdf)
- U.S. Department of Education: Frequently asked questions about Section 504 and the education of children with disabilities (<http://www2.ed.gov/about/offices/list/ocr/504faq.html>)
- U.S. Department of Education: State Listings and Education Information (www.ed.gov/about/contacts/state/index.html)

Resources for learning more about pediatric cardiomyopathy

- Children’s Cardiomyopathy Foundation (www.childrenscardiomyopathy.org)
- American Heart Association (www.americanheart.org)
- National Heart, Lung & Blood Institute (www.nhlbi.nih.gov)
- National Organization for Rare Diseases (www.rarediseases.org)

By working together with parents, students, and health care providers, schools can provide a safe and supportive educational environment for students with cardiomyopathy.



This booklet was created to serve as a reference for families, caregivers, and school personnel. The material presented is not intended to be complete or serve as medical advice. The provided information may not address every need that a child with cardiomyopathy requires in school. In addition, schools may have different ways of developing, maintaining, distributing, naming, and documenting plans and accommodations.

The provided information should not be a substitute for consultation with a qualified health care professional who is more familiar with a child's individual medical conditions and needs. A child's medical situation may vary depending on the type of cardiomyopathy diagnosed, cause, and severity. Each child's plan should be created with his or her specific needs in mind and in consultation with his or her physician.



For more information, visit
www.childrenscardiomyopathy.org.



P.O. Box 547
Tenafly, New Jersey 07670
866.808.CURE
info@childrenscardiomyopathy.org