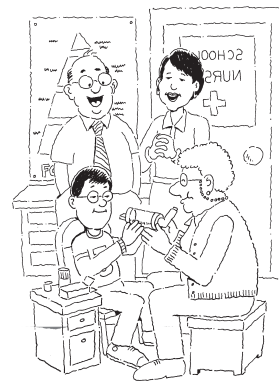


Students With Chronic Health Conditions: Guidance for Families, Schools, and Students



School is more than a place to gain knowledge and skills. It also is a place where children meet new friends and learn about themselves and other important life lessons. Because children spend many hours in school, it is important that it be a safe and supportive environment for all children.

Ten percent to 15% of children in our nation's schools have a chronic health condition (such as asthma, allergies, diabetes, and seizure disorders). Parents, school staff, and pediatricians need to work together to make sure children with chronic illnesses have the same educational opportunities as other students.

Read more to learn how parents, schools, students, and pediatricians can create a safe and supportive place for students with chronic health conditions.

Parent responsibilities

If your child has a chronic illness, how he is cared for and treated at school is important. You will need to work with the school to make sure his health care needs are being met at school, and that he is given the same opportunities to participate in school activities as other students.

The following are ways you can help your child receive the education and services he or she needs to succeed in school:

- **Talk to the school.** Don't be afraid to tell the school about your child's condition. Some parents worry about sharing this information, but the more informed teachers and other school staff are, the better prepared they will be to help your child. If the school staff don't have all the facts, they may make wrong assumptions about your child's behavior or performance.
- **Make a health plan.** Ask your pediatrician to help you write down exactly what the school should do if your child has certain health needs. School staff should know how to reach you or your pediatrician in case there is an emergency. Remember to call the school right away when contact information has changed.

Also, try to plan her medicine or treatment schedule at a time that interferes the least with her classes; the best time may be during lunch or a study break. If your child takes medicine at school, ask about the school's policies for storage and self-usage. For example, if appropriate, schools may let some students with asthma carry their inhalers and use them if needed. Make sure your child is able to take her medicine in a comfortable place, and that the school is provided with an adequate supply. Remember to call the school right away if there are any changes in your child's condition.

- **Give your consent.** Encourage open communication between your pediatrician and the school staff so that everyone who cares for your child has all the facts about his condition. If the school staff have any questions, they should call your pediatrician. You will have to sign a release form that gives the school permission to contact your pediatrician. Also, your pediatrician will need your written permission to discuss your child's condition with the school. If your child requires medicine or special procedures, the school must receive written instructions from your pediatrician.

What does the school need to know?

If your child has special health needs, the school should have a written document outlining a health care and emergency plan. The following information should be in the document:

- A brief medical history
- The child's special needs
- Medicine or procedures required during the school day
- Special dietary needs
- Transportation needs
- Possible problems, special precautions
- Pediatrician's name
- Emergency plans and procedures (including whom to contact)

- **Plan ahead.** Meet with your child's teachers regularly to talk about how your child is doing at school. During parent-teacher conferences, ask if your child's health condition is affecting her schoolwork or behavior. If your child is missing a lot of school due to illness, talk with her teacher about ways to help her keep up with her work. For example, when your child misses school, plan how homework will be sent home.
- **Teach others.** A number of school systems have programs that teach students about chronic illnesses and disabilities. The programs hope to increase awareness and sensitivity among students. If your child is old enough, is willing, and has the school's support, he may want to share his experience with his class. If you're interested, you can find ways to participate in school curriculum committees or with the PTA to help educate parents and students about classmates with chronic health conditions.
- **Know the law.** By law, your child is entitled to an education that will help her develop to her full potential. Schools may be required to provide additional services that will assist in both in-school programs and after-school events. Federal laws such as the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA) state that every child should be allowed to attend school in the "least restrictive" setting possible.

Get to know these laws so you are aware of all the services your child is entitled to. For example, if she needs speech therapy, psychological counseling, or physical therapy to do well in school, the school *must* determine if she is qualified for them and, if so, must then provide them. She also may be eligible for home-based education, *if* the home is the least restrictive setting. Schools only are required to provide health-related services that affect your child's education or are required at school for safety reasons. Parents and health care systems are responsible for the rest.

If your child's educational needs are not being met, the following are some steps you can take:

- **Work with the school.** Ask the teacher and other school staff to meet with your pediatrician to create guidelines to help your child succeed at school. These guidelines should clearly state what the school would do for your child.
- **Know the guidelines for resolving complaints.** There are procedures (spelled out by every school district) through which you can appeal and try to solve any problems. Ask the school for a written copy of these guidelines for resolving complaints.
- **Contact the local board of education.** If you still are not satisfied, contact the local board of education or the regional office of the US Department of Education.

School responsibilities

By law, school districts are required to offer programs that provide children with chronic health conditions with the full range of educational opportunities. Federal laws designed to ensure this happens include the following:

- **ADA (Americans with Disabilities Act)** prohibits discrimination against students in education programs or activities that receive federal funds based on disability.
- **IDEA (Individuals with Disabilities Education Act)** allows children with disabilities to remain in regular classrooms with regular teachers if the student can learn optimally in that environment.
- **Section 504** is a civil rights law that prohibits discrimination against people with disabilities—children with disabilities should be given equal access to education.
- **FERPA (Family Educational Rights and Privacy Act)** is a federal law that protects the privacy of students. Schools are required to obtain written permission from parents before a child's education record can be released. The law also requires schools to release a child's education record to a parent, if requested. Schools may disclose, without consent, "directory" information such as a student's name, address, phone number, birth date and place of birth, honors and awards, and attendance dates.
- **State or local laws and district policies** may require schools to provide different services for students with chronic illnesses. These services often vary by state and school district.

Once the school is informed a student has a chronic health condition, a meeting is often scheduled to discuss what services may be needed. The meeting should include parents, the student (if old enough), school health staff, the coordinator of special needs services, student aids, and the child's primary teacher. Health care providers, such as the child's pediatrician, also should be invited or asked to provide information in writing.

One goal of this meeting is to develop a written plan that clearly describes the services the student needs. Depending on the child's needs, this plan may be described as a 504 Plan or an Individualized Education Program (IEP). This legal document outlines exactly what services the child will receive and sets short- and long-term goals for the child. The plan should be reviewed regularly to ensure it continues to meet the child's needs.

Other school responsibilities include the following:

- **Provide staff training and support.** Schools should provide their staff the training and tools necessary to ensure students' health and educational needs are met. Staff members should be prepared to handle emergencies. There should be a staff member available who is properly trained to give medicine or other emergency care during the school day and at all school-related activities regardless of time or location. Schools should ensure that case management is provided as needed.
- **Promote a supportive environment.** Schools should promote a supportive learning environment that views students with chronic illnesses as the same as other students. Schools should make it as easy as possible for students with chronic illnesses to participate in such school activities as physical education, recess, after-school programs, and field trips. Schools should promote good general health, personal care, nutrition, and physical activity.
- **Provide a safe environment.** Schools should make sure that students can take their prescribed medicine in a safe, reliable, and effective manner, and that it's available when needed.
- **Keep parents informed.** Schools should communicate regularly with parents and with the student's pediatrician (if permission is given).
- **Keep information confidential.** Schools should make sure proper records are kept and that confidentiality is maintained.

Student responsibilities

Include your child as much as possible in all discussions and plans that affect his school experience. This will help your child learn to be an active participant in the care and management of his health. Also, make sure your child has an adult to go to if he has any concerns or needs during the school day. Talk to your child regularly about how he feels his health condition is being managed at school and if any improvements or changes need to be made.

Pediatrician's role

Your pediatrician cares about your child's health and can be an excellent resource regarding school issues. The following are ways your pediatrician can be involved in enhancing your child's school experience.

- **Answer the school's questions.** Your pediatrician should have on file any permission forms that allow her to talk directly to your child's school. Make sure the forms are updated at the beginning of each school year. This is extremely important if the school needs specific medical information about your child's condition. It also can relieve you of having to carry messages back and forth between school personnel and your pediatrician.
- **Provide the school with medical information.** Ask your pediatrician to provide the school with a description of your child's medical, developmental, and safety needs. This should include special precautions the school should take in an emergency.
- **Help the school develop a plan.** Invite your pediatrician to work directly with school staff as they explore ways to meet any special needs your child may have. Pediatricians may not be aware of all options that are available in each school to meet a child's needs, but your pediatrician's input and point of view makes her a valuable member of the school's team.

- **Help improve your child's school attendance.** At your child's check-ups, talk with your pediatrician about your child's school attendance and involvement in school activities (such as physical education programs). For example, while you may think missing 2 or 3 school days each month due to your child's asthma is OK, your pediatrician may be able to help reduce the amount of time your child misses school.

The information contained in this publication should not be used as a substitute for the medical care and advice of your pediatrician. There may be variations in treatment that your pediatrician may recommend based on individual facts and circumstances.

From your doctor

