

504 PREP GUIDE

for *Heart* Parents



PREPARE. ADVOCATE. SUPPORT.

CHD Tablet Talk Foundation

504 Preparation Guide

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What is a 504 Plan? A 504 Plan is named after Section 504 of the Rehabilitation Act of 1973, a federal civil rights law that protects individuals with disabilities from discrimination. In schools, Section 504 helps ensure that students with disabilities have equal access to educational opportunities. These plans and evaluations are available to families at no cost. To be eligible, a student must have a documented physical or mental impairment that substantially limits one or more major life activities. Unlike an IEP, a 504 Plan does not provide specialized instruction; instead, it removes barriers and provides accommodations that allow students to access their education alongside their peers. (US Dept of Education).

Why My Child with Congenital Heart Disease May Need a 504 Plan? A 504 Plan allows parents to clearly communicate the accommodations their child needs to access their education and thrive in school. It is a legally binding document that helps protect your child by ensuring important academic, physical, and health-related accommodations are consistently provided throughout the school day. In some states, 504 Plans may take 30–60 days to be finalized and implemented, so it is recommended that you contact your child's school and schedule a 504 meeting before the start of the school year.

How will this guide help me? In life, we can become so accustomed to the adaptations we make that we may not even realize an accommodation has been made. Over time, it can be easy to forget that we are doing things a little differently than the average person. The goal of this guide is to help you identify the accommodations your child may need as they prepare for school. Keep in mind that not every question will apply to your child, as needs vary by age, grade level, and individual circumstances. There may also be things we've overlooked, so imagine each part of your child's day and consider what additional support they might need. Once you've completed this guide, you'll have a clearer understanding of your child's needs and be better prepared for their 504 meeting. Sharing the completed guide with the school in advance gives teachers and administrators time to review it and prepare any questions they may have. Additionally, consider whether the school nurse should be included to help ensure all aspects of your child's needs are addressed.

Stay Connected: Let us know if this resource was helpful or if there's something we missed that could help other families. You can find us at @chdtablettalk. And remember: you are your child's biggest advocate, and keeping them safe is never "too much."

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IMPORTANT DETAILS TO SHARE WITH THE 504 TEAM:

Medical & Emergency Information

- What are your child's baseline symptoms (e.g., blue lips, fatigue, shortness of breath)?
- Which symptoms should prompt an evaluation by the school nurse?
- Which symptoms should prompt staff to contact you?
- Are staff welcome to contact you anytime they have questions or concerns?
- Which symptoms require an immediate call to EMS/911?
- What is your preferred hospital in the event of an emergency?

Activity & Physical Limitations

- What activities tend to worsen your child's symptoms?
- What physical restrictions does your child have?
- Which restrictions are temporary, and which are permanent?
- What does fatigue typically look like for your child?
- What warning signs appear before your child becomes physically overwhelmed or symptomatic?
- How much recovery time does your child typically need after physical exertion?

School Day Considerations

- Is there anything substitutes, special programming teachers, or support staff should know about your child?
- Are there any additional health, safety, or academic concerns the school team should be aware of?

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BEFORE/ARRIVAL AT SCHOOL:

- Does your child require specialized transportation or a special needs bus?
- Does the bus driver need to be aware of any medical needs, restrictions, or emergency procedures?
- Are there any transportation-related accommodations your child may need?
- Does your child have a lifting or carrying restriction (e.g., backpack weight limits)?
- Does your child need assistance carrying school supplies, books, or technology?
- Are there any immunizations, health requirements, or school-related medical concerns you should discuss with your child's cardiologist before the school year begins?

ABSENCES / TARDINESS: (This is one of the most important sections to consider including in a 504 Plan.)

- Does your child need accommodations for frequent absences or tardiness related to their medical condition, appointments, procedures, or recovery?
- Does your school have limits on excused absences or tardies that should be waived as part of the 504 Plan?
- Note: Parents should still notify the school so absences and tardies can be properly documented and excused.
- Will your child need access to a school-provided tutor or homebound instruction during extended absences?
- If your child misses school for a procedure, hospitalization, or recovery period, will they be granted extended deadlines for makeup work and assignments?
- How will teachers provide missed classwork, notes, slides, and other instructional materials during absences?
- How will tests, quizzes, and major assignments be handled following an extended absence?
- Is there a plan for helping your child catch up after significant missed instructional time?

DURING SCHOOL DAY:

- Academics & Testing
- Does your child need extra time for tests, quizzes, or assignments?
- Does your child need a separate testing environment with fewer distractions?
- Note: A 504 Plan can provide accommodations for how a student is tested, but it cannot change what the student is tested on.
- Would an extra set of textbooks be beneficial (one for home and one for school)?
- Does your child need preferential seating (front of the room, near the teacher, near the bathroom, etc.)?

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 - Does your child need preferential seating (front of the room, near the teacher, near the bathroom, etc.)?
- Mobility & Physical Demands
 - Does your child have restrictions on lifting or carrying heavy items?
 - Does your child need assistance transporting books, supplies, instruments, or technology throughout the school day?
 - Would a student buddy or staff assistance be helpful?
 - Does your child need access to the elevator?
 - Does your child need extra time to travel between classes without being marked tardy?
 - Would it be helpful to keep extra seasonal clothing or snow gear at school to reduce carrying demands?
- Physical Education, Recess & Activities
 - Has your child's cardiologist cleared them to participate in physical education?
 - If not, has the cardiologist provided documentation for a waiver or modified participation?
 - If participation is permitted, does your child need permission to self-limit activities or opt out of specific units (e.g., PACER tests, swimming, contact sports)?
 - How will these accommodations be communicated to substitute teachers?
 - Does your child need recess accommodations during extreme heat or cold?
 - If applicable, should your child be exempt from marching band requirements?
 - Does your child need accommodations for assemblies, field days, or other school-wide events?
- Medical Needs
 - Does your child take medications during the school day?
 - Can medications be self-administered, or will staff require training?
 - Is there a backup staff member trained to assist if the school nurse is unavailable?
 - Does your child take diuretics and require unrestricted bathroom access?
 - Does your child need access to snacks, water, or nutritional support outside designated meal times?
 - Does your child use medical equipment that requires storage, charging, electrical outlets, or other accommodations?
 - Does your child need physical rest breaks throughout the day without academic penalty?

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DURING SCHOOL DAY CONTINUED:

- Emergency Planning & Safety
 - Does your child need accommodations during fire drills, lockdowns, or other emergency drills?
 - Consider noise sensitivity, PTSD responses, physical limitations, evacuation routes, and walking distances.
 - Is there an emergency evacuation plan specific to your child's needs?
 - Are there circumstances under which staff may need to physically assist or carry your child?
- Substitute Teachers & School Staff
 - Should your child's accommodations be specifically highlighted for substitute teachers?
 - Is there any additional information that substitute teachers should be aware of?
 - Field Trips & Special Events
 - Do you need permission to attend field trips with your child?
 - What accommodations will your child need during field trips?
 - Do transportation, walking distance, weather exposure, or activity levels need to be considered?
- Dress Code & Comfort
 - Does your child need dress code accommodations, such as permission to wear athletic shoes, sweatshirts, hats, compression garments, or other medically necessary items?