



# Children with sickle cell disease can stay healthy and succeed at school\*

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Staying healthy at school and getting good grades can be hard for a child with sickle cell disease, but it does not have to be.

- If all teachers knew your child has to drink a lot of water and wear her coat when it is cold, she could probably stay healthier.
- If all teachers followed a plan so your child can make up all the work she misses when she's sick, she could probably get better grades.

The law says your child's school must make and follow a plan to help your child stay healthy and succeed at school. This kind of plan is called a "504 Plan." It explains everything your child needs to stay healthy at school. Also, it can tell the school how to help your child catch up after she is out sick.

## How do I get a 504 Plan for my child?

- 1) Ask your child's doctor to use the forms in this packet so your child can be healthy and successful at school. He or she can look at the sample doctor's letter, "accommodations chart," and medication forms. He or she can change the samples to talk about your child's **specific** needs. See "[Instructions for your child's doctor](#)" on the next page.

- 2) Ask the school for a meeting to create a 504 plan for your child.
- 3) Before the meeting, give the school a copy of the doctor's letter, the chart, and the medication forms for your child. Keep a copy for yourself, and bring copies to the meeting.
- 4) The school must meet with you. Let the school know that you know your rights. Keep asking for the meeting until they schedule it.

## Is a "504 Plan" the same as special education?

No. Students that need special education have Individualized Education Programs (IEP). An IEP is usually for students who have a hard time learning, even if they can attend class. A 504 plan is more for students who might fall behind because of a disability that makes them sick so they cannot attend class.

To see a chart that shows the differences between IEP's and 504 plans, see <http://www.nclد.org/disability-advocacy/learn-ld-laws/adaaa-section-504/section-504-idea-comparison-chart>

To learn more about IEP's, see <http://fcsn.org/parents-guide>

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\* This guide provides information **not** advice. To find out what to do about your own legal problem, speak with a lawyer.

# Instructions for your child's doctor

Form	Instructions for doctor
<p>Doctor's cover letter</p>	<ul style="list-style-type: none"> <li>• Individualize the letter by changing the highlighted text. This primarily involves making basic changes (inserting the patient's name, your name, etc.)</li> <li>• If your patient has any additional unique needs such as a hip necrosis, asthma, etc., there is a section at the bottom where you can add this information.</li> </ul>
<p>Accommodations chart</p>	<ul style="list-style-type: none"> <li>• Individualize by inserting the child's name/etc. in the appropriate places.</li> <li>• In the chart, plain text shows accommodations that all children with SCD need. Highlighted text indicates places to add any additional accommodations your patient requires based on their unique needs. Delete this text if it is not needed.</li> <li>• The final row about absences is crucial. Make sure the parent and school focus on this.</li> </ul>
<p>Medication forms</p>	<ul style="list-style-type: none"> <li>• Two forms are included for you (note that parents must sign these forms):               <ul style="list-style-type: none"> <li>➤ The first form is mostly filled and is for Ibuprofen (if the child is not allergic).</li> <li>➤ The second form is blank. If the child needs any medications at school besides Ibuprofen, print and complete one of these forms for each medication.</li> </ul> </li> </ul>
<p>Final packet</p>	<ul style="list-style-type: none"> <li>• Give copies to the parent/guardian(s) and support them in their advocacy with the school.</li> </ul>

## CLINIC HEADER

### Date

504 Coordinator

School Name, School District Name

Address

City, State, Zip

Fax: (123) 456-7890

**RE: Necessary Accommodations and Request for 504 Plan for John Doe**

Dear Sir or Madam:

**John Doe** (DOB: 11/11/01) is under my care at the **Pediatric Hematology program** at **Hospital**, and I am writing on behalf of **John's mother, Jane Doe**. **John** has sickle cell disease (SCD). SCD refers to a group of genetic blood disorders, the most common of which is sickle cell anemia (HbSS). Individuals with SCD experience a number of complications, including severe anemia, susceptibility to infections, and unpredictable episodes of debilitating pain. These pain episodes can lead to hospitalizations and have life-threatening consequences.

Under various circumstances, the blood cells of a person with SCD can deform from a flexible doughnut shape into a rigid sickle shape (hence the name). When enough cells have sickled, the deformed cells can collectively block small blood vessels, which deprives the surrounding tissue of oxygen. This causes it to die and leads to high levels of pain. Notably, anything that makes sickling of the cells more likely, constricts the blood vessels, or increases the concentration of blood can make a pain episode more likely.

As a result, pain episodes can be triggered by exposure to cold, exposure to heat, dehydration, overexertion, stress, and poor medication management. Exposure to cold constricts blood vessels, making it easier for them to become blocked and cause a pain episode. Exposure to heat increases the likelihood of dehydration and overexertion. Dehydration increases the concentration of blood, making a blockage and resulting pain episodes more likely; overexertion reduces the blood oxygen concentration, making sickling of the cells and resulting pain episodes more likely. Finally, stress and poor medication management can also bring about physiological changes that make pain episodes more likely.

Many pain episodes can be prevented or reduced in severity by reducing exposure to these triggers. That said, some pain episodes and other complications are simply unpredictable, and so **John** is still likely to have several unpredictable absences of varying frequencies and lengths.

[If relevant, add an additional paragraph here to describe any additional issues specific to this child that might require additional accommodations (e.g., hip necrosis, asthma, etc.). Note: obtaining an IEP is a separate process (a 504 plan is different than an IEP).]

As a result of the above, **John** requires a 504 plan that includes all of the accommodations listed in the attached document(s) in order for him to access the curriculum at school. Thank you very much for your consideration in developing such a plan for **John** as soon as possible. With the family's permission, I would be happy to provide any additional information that might be helpful in this process.

Sincerely,

Dr. **Pat Smith**, MD

617-123-4567; [Pat.Smith@hospital.org](mailto:Pat.Smith@hospital.org)

Cc: **Jane Doe**

Encl: Accommodations Chart & Medication Form(s)

## CLINIC FOOTER

SCHOOL-RELATED ACCOMMODATIONS FOR JOHN DOE

**What is Sickle Cell Disease (SCD)?**

SCD refers to a group of genetic blood disorders, the most common of which is sickle cell anemia. Individuals with SCD experience a number of symptoms, the most challenging of which are unpredictable episodes of debilitating pain. These pain episodes can lead to hospitalizations and have life-threatening consequences. Episodes can be caused by exposure to cold, overexertion, dehydration, stress, and poor medication management.

**How to help John stay healthy and succeed in school**

With proper accommodations and supports at school, many pain episodes can be prevented or reduced in severity, and children with SCD like John can excel academically and grow up to live full and productive lives. Given John's condition and his unique needs, he requires at a minimum the following accommodations, which should be incorporated into a 504 plan:

Focus Area	Accommodations
Everywhere	Privacy: given inaccurate historical stigmas associated with SCD, privacy is especially important. That said, any adult providing one of these accommodations should be aware of their responsibility to do so.
Before and after school, and during recess	<ul style="list-style-type: none"> <li>• Allowance to stay/wait inside when it is cold or hot outside: when waiting for school to open, waiting for their ride to take them home, or during recess or other outdoor activities, it is important for kids with SCD to be able to stay inside when it is very cold or hot in order to avoid exposure to high and low temperatures.</li> <li>• Door-to-door transportation: [MEDICAL PROVIDER: this is needed when there is a mobility impairment like hip necrosis, and/or when the child has to walk far to the school or nearest bus stop; if you include this accommodation, please list the reason here].</li> </ul>
At School	<ul style="list-style-type: none"> <li>• Extra set of textbooks: one for home and one for school</li> <li>• Allowance to carry water/access water fountains at all times: staying hydrated is very important</li> <li>• Allowance to use bathroom at all times</li> <li>• Allowance to wear coats/jackets at all times: it is very important for kids with SCD to stay warm</li> <li>• Elevator access and a few extra minutes to move between classes</li> <li>• Modified participation in gym/allowance to rest when needed</li> <li>• A medication plan, as well as allowance to visit the school nurse when experiencing symptoms. <b>See attached medication authorization letter(s).</b></li> <li>• [MEDICAL PROVIDER: Some children with SCD will have assistive technology needs, such as the need to type notes instead of writing them due to hand writing being more painful. If this child has any of these needs, or any other needs based on additional medical conditions, include them here and provide more information in the letter above. Note: obtaining an IEP is a separate process (a 504 plan is different than an IEP)]</li> </ul>
Absences, assignments, and tests	<ul style="list-style-type: none"> <li>• Children with SCD will have numerous, somewhat unpredictable absences of varying frequencies and lengths. As such, it is absolutely critical to put a plan in place to help them fall behind as little as possible when absent and catch up as quickly as possible afterwards. Such a plan should include:               <ul style="list-style-type: none"> <li>➢ Whenever the child is absent, generation and communication of a list of all missed learning (lessons, activities, projects etc.), all missed assignments, and all missed tests.</li> <li>➢ Allowance for reasonable timeframe to make up missed assignments and to study for and take tests.</li> <li>➢ Until fully caught up, access to a tutor at home and in the hospital who will have access to the list of all missed learning, assignments, and tests, and who will help assure the student (i) catches up on all missed learning, (ii) completes missed assignments, and (iii) studies for and takes missed tests.</li> </ul> </li> <li>• [MEDICAL PROVIDER: Some children with SCD will have additional needs, such as type assignments instead of writing them due to hand writing being more painful. If this child has any needs like this, include them here and provide more information in the letter above]</li> </ul>

**Authorization Letter for Dispensing Medication (Including OTC's) in School**

**Parent/Guardian:**

I request that my child, \_\_\_\_\_, receive medication as prescribed in the form below, by Dr. \_\_\_\_\_ in the form below.  
Name of Physician

\_\_\_\_\_  
Signature of Parent/Guardian

Telephone Number: \_\_\_\_\_

Date: \_\_\_\_\_

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**Physician:**

I request that my patient receive the following medication:

Name of Student: \_\_\_\_\_

Diagnosis: **Sickle Cell Disease** \_\_\_\_\_

Name of Medication: **Ibuprofen** \_\_\_\_\_

Prescribed dosage & time to be taken during school hours: **Per the details on the bottle dispensed** \_\_\_\_\_

Indication: **Sickle Cell related pain, fever, or if directed to give by parent or provider** \_\_\_\_\_

Expected duration of treatment: **Indefinite; intermittent throughout the school year** \_\_\_\_\_

Possible side effects and adverse reactions: **\*See below for details** \_\_\_\_\_

Physician's Telephone: \_\_\_\_\_

Fax: \_\_\_\_\_

Physician's Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Physician Signature: \_\_\_\_\_

Date: \_\_\_\_\_

N.B. This form must be completed and signed by both the parent and the prescribing physician. Please return it to the school nurse. Medication cannot be administered without this completed and signed form on file in the office of the school nurse.

**\*Ibuprofen Information**

Ibuprofen is a non-steroidal anti-inflammatory pain relievers, which means it is effective against the pain and inflammation associated with sickle cell vaso-occlusive pain. Correct dosing is by weight (10mg/kg), and should be listed for each child on their sickle cell self-care plan. Approximate doses by age are 200mg every 6-8 hours for elementary school children, and 400-600mg every 6-8 hours for older children. Ibuprofen should start working in 30 minutes, and lasts up to 6 hours. No more than 4 doses should be given in a 24-hour period. Ibuprofen is the active ingredient in Motrin and Advil, and is contained in many other over the counter medications. If patients are already taking ibuprofen or aspirin containing cold medicine they should not take more ibuprofen. The most common side effect of ibuprofen is upset stomach, which can be avoided by giving the medication with a small amount of food (crackers or juice are fine). Ibuprofen should not be given to people who are allergic to aspirin. In rare cases ibuprofen can cause bleeding from the stomach or worsening kidney problems; if there are any concerns please contact the student's physician immediately.

**Authorization Letter for Dispensing Medication (Including OTC's) in School**

**Parent/Guardian:**

I request that my child, \_\_\_\_\_, receive medication as prescribed in the form below, by Dr. \_\_\_\_\_ in the form below.  
Name of Physician

\_\_\_\_\_  
Signature of Parent/Guardian

Telephone Number: \_\_\_\_\_

Date: \_\_\_\_\_

\*\*\*\*\*

**Physician:**

I request that my patient receive the following medication:

Name of Student: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Name of Medication: \_\_\_\_\_

Prescribed dosage & time to be taken during school hours: \_\_\_\_\_

Indication: \_\_\_\_\_

Expected duration of treatment: \_\_\_\_\_

Possible side effects and adverse reactions: **\*See below for details**

**Physician's Telephone:** \_\_\_\_\_

**Fax:** \_\_\_\_\_

**Physician's Address:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Physician Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

N.B. This form must be completed and signed by both the parent and the prescribing physician. Please return it to the school nurse. Medication cannot be administered without this completed and signed form on file in the office of the school nurse.

**\*Medication Information**

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