

Reasonable Accommodations for College Students with Sickle Cell Disease

What are "reasonable accommodations"?

Some of the rules at college make it hard to succeed if you have a disability. Reasonable accommodations are the changes that colleges make to these rules to help students with disabilities succeed.

If you have a disability, the rules about how many courses you have to take each semester, how many classes you can miss, or when the heat is turned on in the dorms may make it hard for you to succeed.

Colleges count sickle cell disease (SCD) as a disability. If SCD makes it hard for you to follow a rule at college, the college **may** have to change the rule. But the college only has to make "reasonable" changes. If a rule makes it hard for you to succeed, you owe it to yourself to ask for a reasonable accommodation.

What accommodations are "reasonable"? What can I ask for?

In college, you can ask for 2 types of accommodations: non-academic and academic. Non-academic accommodations are usually simpler and easier to get than academic accommodations.

Non-academic accommodations

Non-academic accommodations help students stay healthy. They also help students make it to class. For example, you might ask to:

- have the heat for your dorm room turned on earlier in the year than usual;
- stay in a dorm closer to classes if getting to class is hard. It could be too painful, too hot, or too cold outside if you have to walk a long way;
- use the elevator in a building if you have a class on a high floor; or
- be able to call the campus shuttle to get to and from class when walking any distance would be hard. Many colleges have shuttle programs like this.

Academic accommodations

Academic accommodations can be more complicated. They include things like making up tests you missed, or taking fewer classes.

For example, if you are in the hospital during a final exam, then it **is** reasonable to ask to make up the exam within a few weeks after you feel better. **But**, it is probably **not** reasonable to ask to skip the exam and still pass the class.

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

The federal rule called “45 CFR 84.44 - Academic adjustments” explains the kinds of academic accommodations a college might have to give you. They are:

- Changing the amount of time the college gives you to finish your degree.
- Taking a different course instead of a required one. This accommodation can be hard to get.
- Changing the way a professor teaches a specific course. This accommodation can be hard to get.
- Recording classes. Ask ahead of time so people have time to set up the equipment.
- Changing the way you take exams, like allowing you to:
 - take them in another room,
 - have more time to take them,
 - have someone read the questions out loud to you, or
 - use a computer or special equipment.
 - Not all students with sickle cell need these accommodations for exams, but ask for them if you need them.

You can see this federal rule at:

www.law.cornell.edu/cfr/text/45/84.44.

You can also show it to your college.

What makes an academic accommodation “unreasonable”?

If an accommodation would change an “essential” part of an academic program, it is not “reasonable” and your college does not have to give it to you. The college decides what is “essential.” The college has a lot of power to decide what

accommodations are reasonable. If you disagree with the college, you can use your college’s grievance procedures, or you can take your college to court.

So, it is very important to get professors, the disability office, and mentors on your side. You need people who **want** to help you. See the “important tips” section below.

Note: an accommodation might be reasonable for one student but not another. Your college might have to give you an accommodation, even if they did not give it to someone else. Every student is unique so the college must look at your request for an accommodation based only on your circumstances and needs.

Does my college have to give reasonable accommodations?

Yes. Every college that gets federal funding must give reasonable accommodations to students with disabilities.

Almost every public and private college gets some sort of federal funding. So, they must give reasonable accommodations.¹

Is this any different from high school?

Yes. Getting reasonable accommodations in college is different from getting them in school.

¹ The two most important laws about this topic are the Rehabilitation Act of 1973 and the Americans with Disabilities Act.

K-12 Schools

In kindergarten through 12th grade, schools must look for children with disabilities that can hurt their education. Once the school knows about a child with a disability, the school must follow many laws to make sure the child has every chance to get the help they need.

College

Colleges do **not** have to **look** for students with disabilities. Even if a college knows you have a disability, it only has to help **if you ask for help**.

To get reasonable accommodations at college, you need to:

- know what to ask for,
- know how to ask,
- ask as soon as you can, and
- follow up many times to make sure you get the accommodations you need.

How do I ask for reasonable accommodations?

1. Research the process for requesting reasonable accommodations at your college as soon as possible.
2. Use your college's process to make your requests with this guide's 10 Steps. See the 10 Steps on the next page.
3. Follow up.

Research the process

Look up your college's rules for reasonable accommodations as soon as you know where you are going.

All colleges have rules about disability and reasonable accommodations, but the rules are different from one college to another:

- Some colleges have a whole office just for handling reasonable accommodation request. Other colleges have just one "disability officer" who also does several other jobs.
- At some colleges, you might start the semester with an in-person meeting. At others, you might have to fill out paperwork online or in person.
- Some colleges may have the same process for all accommodations. Other colleges might have one process for housing accommodations and a different process for academic ones.
- **Note:** many colleges ask that you request housing accommodations months ahead of time.

Follow the process: 10 Steps

As soon as you know where you are going to college:

1. Figure out how the school wants you to ask for the accommodations you need. Go online, call the disability office, and read the materials the college sends you.
2. Contact the disability office or officer. Your college may use a different name for this office.
3. Let the disability officer know you are a student with a disability. You may have to fill out a form online or find them in person.
4. They will probably have forms to ask for reasonable housing accommodations. Many schools require you to ask for reasonable accommodations months ahead of time.
5. Get the forms or write a letter that explains the reasonable accommodations you are asking for
 - a. See the section above called “What accommodations are reasonable? What can I ask for?”
6. Ask for the specific accommodations you need on the right forms. If there are no forms, ask in a letter.
7. Meet with the disability officer if your college allows you to, even if you already filled out the forms. Help them get to know you. Let them know you want you to succeed.
8. Collect the proof that you have a disability—get a letter from your doctor. See the section below called “Medical documentation.”

9. Prove that you need the accommodations you are asking for because of your disability. Give the disability officer letters from your doctors.
If necessary, negotiate with the college over what accommodations they will grant. It should not be all or nothing. If they do not want to give you the accommodation you asked for, see if there is a different accommodation that they *will* give you that will help you in the same way.
10. If you need a reasonable accommodation for a particular course, the disability office usually tells you to talk to the professor first. If the professor says no or gives you a hard time, ask the disability office to help. They can help you talk with the professor to solve the problem. This can feel scary. But remember: the purpose of the disability office is to help students get the accommodations they need. If you do everything you can to get the accommodations you need now, you are less likely to have problems later.

Medical documentation

Your college will probably want proof and an explanation of your disability. A doctor’s letter or medical records should be enough. See the sample doctor’s letter at the end of this guide. Give this sample to your doctor and ask for a letter that is about your particular situation. The college may also need copies of your medical records or letters about specific hospitalizations.

Follow up

Do whatever it is you need to do to make sure you actually have the accommodations you need when your classes start. Write emails, make phone calls, and visit the disability office. Never assume that you will get your accommodations unless you have something that officially tells you so. Do not wait around if you do not hear back: check-in with the disability office and find out what is happening with your request.

Important tips

1. Find a dean you admire or who is interested in the same things as you. Meet with him or her. Tell him or her about your experiences and what you want to achieve. Make them see that your success is their success. Having a mentor on campus, someone with power on your side, can be very important. They may be able to help if you end up needing a reasonable accommodation that a professor does not want to give you.
2. You want your professor to agree to give you a reasonable accommodation the **first time** you ask. Some professors may not agree right away even if your request is reasonable. So, in addition to making sure your request is reasonable, you need to think about **how you ask**. Think about the professor's style. Is this

something she would prefer to talk about:

- over email?
 - during office hours?
 - in person, right after class?
3. When you talk to your professor, explain how the accommodations fit into your long-term goals.
 - **Do say:** "This class is important to my career goals. I do not want to miss any of the material. I do not want being sick to hold me back."
 - **Do not say:** "I was sick so you have to let me make up that class."
 4. **Go to the disability office, deans, and professors early.** If you can get your disability officers, deans, and professors to invest in you and want you to succeed, it will be much easier to get the accommodations you need.
 5. Carefully plan your classes and activities in a way that makes sense for you. This does not mean that you have to limit yourself, but knowing that SCD is serious can help you plan around the complications it can cause.

Many students with SCD succeed in college! Asking for reasonable accommodations can help you succeed as well. You owe it to yourself to ask for the accommodations you need.

SAMPLE DOCTOR'S LETTER

HOSPITAL LETTER HEAD

Clinic Header

Disability Office
New England University
123 University Lane
Town, State 12345

Re: Jane Doe (DOB: 6/15/1995)
123 Student Street
City, State 67890

To Whom It May Concern:

Jane Doe is under my care in the Pediatric Hematology Program at Hospital for her sickle cell disease, an inherited disorder of the red blood cells.¹ Jane was diagnosed at birth with HbSS, a severe form of sickle cell disease, and has already suffered many complications of the disease, including infections, pain, and organ damage. Like many patients with sickle cell disease, Jane can be well for periods of time, and then have painful crises or other complications that have required emergency department visits or hospitalizations.

Jane is a very bright and talented young woman who has done very well despite dealing with a debilitating disease. That said, it is important to note that despite optimal medical care there is no way to eliminate these complications entirely, or to predict when they will occur. I anticipate that Jane will have to miss class periodically due to her illness in the future and would ask for all

¹ Under various circumstances, the blood cells of a person with sickle cell disease (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, depriving 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, among other things, exposure to very cold and hot temperatures, airway irritants, poor nutrition, dehydration, overexertion, stress, and delayed medical 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 and airway irritants both reduce blood oxygen concentration, making sickling of the cells and resulting pain episodes more likely. In addition, stress and poor medication management can bring about physiological changes that make pain episodes more likely. Finally, people with SCD are at a significantly increased risk of infection and can have a hard time fighting infections. Such infections can also lead to a pain episode.

Many pain episodes can be prevented or reduced in severity by reducing exposure to these causes of pain episodes and infections. That said, some pain episodes and other complications are simply unpredictable, and so Jane is still likely to have some unpredictable hospitalizations of varying frequencies and lengths.

allowable accommodations under relevant state and federal laws to be made to enable her to view missed content, complete missed assignments, and take missed exams.

Furthermore, as noted in the footnote, certain circumstances such as exposure to cold are known to exacerbate the complications of sickle cell disease, and mobility can be impaired due to anemia and pain episodes. Therefore, Jane should have on-campus housing close to her classes and if necessary have transportation available to reduce the distance she walks and the time she spends outside in very cold or hot weather. She should be placed in a first floor or elevator-accessible room, and she should be allowed to control the heat in her room at all times.

Please let me know if there is any other information that I can provide.

Sincerely,

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