

Sickle Cell Disease & Housing*

People with sickle cell disease (SCD) have to think carefully about their home. Being too cold at home is a problem for anyone, but for someone with SCD it can cause a pain crisis.

This guide has information on two topics:

- **Housing Conditions:** how to get your landlord to fix problems like rats and broken radiators.
- **Reasonable Accommodations:** how to get your landlord to change a rule or the way she usually does things. If a rule or “business as usual” is harming your child because of her SCD, your landlord might have to make a change.

Housing Conditions

Problems with “housing conditions” are problems like broken pipes, broken heaters, mold, and rodents. If your apartment has serious problems like these, your landlord must fix them.

What can I do if my apartment has bad conditions?

1. Write to your landlord about the problem. List all the problems. Date it and sign it.
2. Keep a copy of the letter. It will help you prove that you told the landlord about the problem. If your landlord does not fix the problem, write follow-up letters to make sure the landlord knows the problems are still there. Take pictures of the problems if you can.
3. If the landlord tries to fix the problems, keep a record. Write down the date of each repair and the work that was done on that date. Write down whether the repair fixed the problem, or not.
4. Keep your copy of the letter and the record of repairs in one place.

What can I do if my landlord will not fix the problem?

1. In most states, cities are in charge of forcing landlords to follow the law. If your landlord does not fix the problems, call your city’s main office. Ask to be connected with the department that inspects housing. This is usually part of the board of health or an inspections department.
2. Explain the problems. Say how long you have had the problems and when you told your landlord.
3. Ask for an inspection. You may get help faster if you tell them your child has a chronic illness and the problems pose a serious risk to your child’s health.
4. You need to be at home when they come to do the inspection. It can take weeks to get another inspection if you miss the first one.
5. The inspector should give your landlord citations if the problems are serious.
6. Ask the inspector to send you a **certified** copy of the report to keep for your records. If the inspector does not give you a certified copy, go to the inspection office and ask for a certified copy.

What if my landlord still does not fix the problems or tries to get back at me?

- Call your local legal aid office. Share all of the documents and records you have collected with them.
 - In Massachusetts: www.MassLRF.org
 - Outside of Massachusetts: www.ptla.org/legal-services-links
- Call the inspector. Report what is or is not happening.
- Call your city’s office of civil rights.

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

Reasonable Accommodations

Landlords have many rules tenants must follow. For example, a landlord might have a rule that says you cannot add a safety grab bar in your bathroom.

Landlords also have their usual ways of doing things. For example, the landlord may turn the heat on or off for the whole building on certain dates every year.

If a rule or “business as usual” causes a problem for a tenant with a disability, **sometimes** landlords have to change the rule or how they do things. This kind of change is called an “accommodation.” But landlords only have to make “reasonable” changes. For example, adding a safety grab bar in a bathroom is probably reasonable, but completely changing a bathroom might not be.

You may ask for reasonable accommodations for your child if he or she has sickle cell disease. Different types of housing have different processes for requesting reasonable accommodations. If you live in public housing, get a housing subsidy, or you live in a larger complex, ask the management office or your case worker for reasonable accommodation request forms. If you cannot get the forms, write a letter. If your landlord rents only a few apartments, you may just write a letter. For all landlords:

1. Write your request for reasonable accommodations,
2. Get a medical letter to support your request,
3. Follow-up, and
4. Keep copies of all the forms, documents and letters you give and get from your landlord .

Writing the request

There are many accommodations that children with sickle cell disease may need to stay healthy. If your child has other needs also, you can ask for accommodations for those needs in the same letter.

When you write the request:

1. Explain **why** your child needs accommodations, and
2. explain the accommodations your child needs.
3. Keep a copy of your request. Samples are included below.

Note: Not all of the requests below will apply to every housing situation.

Sample reason for why accommodations are needed:

My 10 year old daughter Jane has sickle cell disease. She is chronically at high risk for developing debilitating pain episodes, overwhelming infections, stroke, acute chest syndrome and pulmonary compromise. Many factors can trigger exacerbations of her illness and cause life-threatening complications. These factors include, among other things, exposure to airway irritants (e.g., mold, dust, cold air, drafts, rodents, insects, and second-hand smoke), exposure to more than a few people (each person carries additional dust, allergens, and exposure to others with infections), delayed medical management when symptoms begin, exposure to the cold, exposure to heat, dehydration, poor nutrition, overexertion. In addition, Jane has had complications arising from her sickle cell disease, specifically avascular necrosis of the hip, that has makes stairs extremely difficult for her.

Sample list of requested accommodations:

Based on her medical conditions, it is essential for Jane’s health that she live in a home that:

1. Is free of free of toxins (including second-hand smoke), mold, dust, dirt, and infestations: please take care of the infestations and mold problems I have told you about.
2. Provides temperature control: please allow us to control the thermostat in our unit instead of having our heat turn only or off with the heat of the building.
3. Is within close proximity of Jane’s medical home, Academic Hospital.

4. Allows for Jane to have her own room (to minimize the risk of exposure to infection and airway irritants): please approve our request to transfer to a unit with one extra bedroom so that Jane can have her own room.
5. Has a functioning kitchen so that I can prepare nutritious meals for Jane that will help sustain her immune system: please fix the refrigerator problem that I told you about.
6. Does not require multiple flights of stairs to access: please approve our request to transfer to a unit that is on the first floor or in a building with a working elevator.

These samples talk about bad housing conditions. If bad housing conditions are especially bad for your child's health because of sickle cell disease, then this can be both a conditions problem and a reasonable accommodations problem.

The Medical Letter

If your landlord wants your child's doctor to fill out a specific form, ask your child's doctor to **both** complete the form **and** write a medical letter. If there is no specific form, ask your doctor for a medical letter. If your landlord wants you to write the request first and then get the medical letter later, it is still OK to give him or her everything at once to save time.

At the end of this guide, we have included 2 sample medical letters and a tip sheet for your child's doctor. When you ask your doctor for a letter, show him or her these samples and the tip sheet. They should make it easy for the doctor to write medical letters for reasonable accommodations in housing.

Once you have the letter and any forms from your child's doctor, keep extra copies for yourself before you give them to your landlord.

Follow-up

After you give your landlord the request for reasonable accommodation and medical letters, follow up every week or two. Write and ask the landlord for updates on your request. Sign and

date the letters, and keep copies with your records. If the landlord ignores your request:

- Your local legal aid office may be able to help. Show the legal aid attorney all of the documents and records you have collected. You can find legal aid offices online:
 - in Massachusetts: www.MassLRF.org
 - outside of Massachusetts www.ptla.org/legal-services-links
- You can also contact your city or state's office of civil rights. Explain that you would like to file "a civil rights complaint because of discrimination based on disability." Explain the situation and show them all of the documents you have kept. Ask for help with filing the complaint.

For more information

For **housing conditions**, see:

www.MassLegalHelp.org/housing/bad-conditions

For **reasonable accommodations**, see:

www.MassLegalHelp.org/housing/accommodations

Other housing problems can also harm your child. See www.MassLegalHelp.org/housing for help with problems like gas and electric bills, discrimination, eviction, and foreclosure.

APPENDIX

General tips re: physician letters for reasonable accommodations in housing contexts

- Your letter must be on official stationery (otherwise it may be assumed to be forged). It must include your personal contact information. If the housing provider wants to follow up with you, it should not be a matter of central switchboards and generic voicemails.
- Start with who you are, what kind of medical professional you are, and your relation to the person with a disability. Unless you have known the patient for only a very short time, state how long you have known the patient.
- Be as specific as possible about as much as you can (see below).
- There are three big things you are trying to communicate here: i) that there is a person in the household who has a disability, ii) that this disability, in the context of the current situation, *requires* the specific accommodation(s) you are requesting, and iii) that the person reading this letter should care about this situation and actually do something about it.
- With that in mind, describe the disability as much as you can (caveat: see note below about whether or not to mention the specific disability) so that it is clear that it is a disability. Educate them about the condition and then give the facts pertaining to this particular person's experience with the disease (i.e. hospitalizations/etc.) to contextualize it and raise their sympathy. Remember that the definition of disability is relatively broad in many housing contexts. One general idea to have in mind is a condition that affects a major life function—that can be thinking, decision-making, and other mental functions as well as walking, breathing, climbing stairs, etc.
- Then describe various ways in which a housing situation can exacerbate and/or be very difficult for a person with this condition generally, this person specifically (see sample), and how an improvement in the housing situation would improve the patient's health.
- Then, and of critical importance, provide the specific ask(s), making clear that each is necessary AND explaining why each is necessary (see sample).
- [OPTIONAL]: Finally, if relevant/you have these facts, you can give additional facts about this particular living situation. For example, you might add the fact that the current place has dust and an old carpet that are harming the kid's breathing and making a pain episode more likely.
- NOTE regarding disclosing the specific disability: You are not legally required to disclose the disability. That is good thing in cases where someone is and/or feels particularly stigmatized by the relevant disability or perceived disability. HOWEVER, there are two catches to this to consider. First, if you are not going to disclose, then it is harder to craft a persuasive letter—you will have to make sure to walk through how the undisclosed disability requires the specific accommodations you are requesting, but doing so without disclosing (or practically disclosing) takes time. Again, it can be worth it and important in certain cases, but bear the added difficulty in mind. Second, stigma is one side of a double-edged sword, with the other side being sympathy. At the end of the day, if you can get the administrator reading your letter to be sympathetic, then you are much more likely to yield effective (let alone any) action. Generating this sympathy without disclosing/describing the disability can make this more difficult. With all that in mind, I generally end up disclosing and then going into a lot of specifics. You should of course have a conversation about all this (pros/cons/etc.) with the family if you are thinking of disclosing.

SAMPLE LETTER 1

Note: this sample is about a family's placement in a government shelter program, but much of the language will apply to other situations as well.

[HOSPITAL OR CLINIC STATIONERY]

[SPECIFIC CLINIC HEADER]

DATE

To Whom It May Concern,

John Doe (DOB: **11/11/01**) is under my care at the **Pediatric Hematology program** at **Hospital**. **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 symptoms, 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, among other things, exposure to cold, airway irritants (i.e. such as second-hand smoke, dust, mold, allergens, rats, and insects), poor nutrition, exposure to heat, 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. Finally, stress and poor medication management can also bring about physiological changes that make pain episodes more likely.

In addition, people with SCD are at a significantly increased risk of infection and can have a hard time fighting infections. As a result, exposure to too many people can increase the chance of someone with SCD developing a serious infection. Moreover, such infections can also lead to a pain episode, making this issue especially important.

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 **John** is still likely to have some unpredictable hospitalizations 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., necrotizing pneumonia, hip necrosis, asthma, etc.).]

Based on **John's** medical conditions, it is essential for xxxx's health that this family be provided with a shelter placement that: (1) is free of free of toxins (including second-hand smoke), mold, dust, dirt, and infestations; (2) will shelter them from cold weather (especially drafts) and provide adequate heating; (3) will shelter them from excessive heat and provide adequate cooling; (4) is within close proximity of a tertiary medical center, such as xxxx's medical home Boston Children's Hospital; (5) allows for xxxx to have her own room and own bathroom (to minimize the risk of exposure to infection and airway irritants); (6) is not crowded and involves living with a very limited number of families (again, to minimize the risk of exposure to infection and airway irritants); (7) has a kitchen so that Ms. xxxx can prepare nutritious meals for xxxx that will help sustain her immune system; and (8) does not require multiple flights of stairs to access.

John *requires* all of these accommodations in order for him to be safe in his housing situation. Currently, it has been reported to me that **John** and his mother are living at the **First Street Shelter** at **ABC First street** and that the conditions and structure of this placement are not in line with the requirements just specified. Among other things, in this placement **John** is regularly exposed to high numbers of people, both where he sleeps and in the bathroom; there is no kitchen in which **Ms. Doe** can cook healthy meals for **John**; and there is a significant amount of old carpeting that generates dust and allergens as people walk over it. This situation is causing immediate risk to **John**'s health.

Thank you very much for your prompt consideration in developing such accommodations 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. **Kim Smith**, MD

617-123-4567;

Kim.Smith@localhospital.org

SAMPLE LETTER 2

Note: this sample is about a family in public housing, but much of the language will apply to other situations as well.

[HOSPITAL OR CLINIC STATIONERY]

[SPECIFIC CLINIC HEADER]

DATE

Dear Sir or Madam,

Jane Doe (DOB: 11/1/2001) is under my care at the Pediatric Hematology program at Hospital. Jane has sickle cell disease (SCD). Please note that Jane's father, **John Doe**, also has SCD and has been a patient of Hospital for many years.

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 (also known as pain "crises") can lead to hospitalizations and have life-threatening consequences. They cause tissue and organ damage as well. Jane has had many of these complications, including hip necrosis (hip tissue death), requiring a surgical procedure known as hip coring.

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.

Jane's and John's housing (please note that their housing needs are identical):

As a result of their medical conditions, it is very important for their health that their home have the following features:

- 1) Temperature control: being too warm or too cold can trigger a pain episode. Moreover, the exact temperature range needed for a patient may vary from day to day. Therefore, what is important is having enough control over the temperature such that the living space can be consistently adjusted (warmer or cooler) as necessary without overshooting. Also, the range of temperatures that a patient may need to experience to stay healthy generally fall between 68° and 85° Fahrenheit.
- 2) No stairs: especially given the hip complications that Jane and John have had, it is critical that they live in a unit with no stairs. This could either be a unit on the first floor, or a unit in a building where there is always a functioning elevator.

* As a result, pain episodes can be triggered by, among other things, exposure to cold, airway irritants (i.e. such as second-hand smoke, dust, mold, allergens, rats, and insects), poor nutrition, exposure to heat, 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. Finally, stress and poor medication management can also bring about physiological changes that make pain episodes more likely.

In addition, people with SCD are at a significantly increased risk of infection and can have a hard time fighting infections. As a result, exposure to too many people can increase the chance of someone with SCD developing a serious infection. Moreover, such infections can also lead to a pain episode, making this issue especially important.

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

- 3) Intercom: especially given that both Jane and John have SCD and have had hip complications, it is important that they can allow emergency personnel into their building easily during emergencies.
- 4) Airway irritants: the unit should be free of free of toxins, mold, dust, dirt, and infestations (such as mice/rats and cockroaches);
- 5) Proximity to their medical home, Hospital: it is important that they live near Hospital. Hospitals that are not tertiary medical centers with specialization in SCD, such as Hospital, cannot provide care that is as appropriate for their complex needs.
- 6) Other needs: there are other needs, such as having a kitchen and avoiding situations with overcrowding that are very important as well. These do not appear to be problematic at the moment, however.

Jane and John need all of these accommodations in order to be safe in their housing situation. If there is no unit with all of these features, units with more of these accommodations will typically be better (though of course still not ideal).

Thank you very much for your prompt consideration in developing such accommodations for this family 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. Vanessa Smith, MD, MSc

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Vanessa.Smith@hospital.org