



Self-Care excerpts from “Hope and Destiny Jr” Hilton Publishing 2019

EXERCISE? STAYING ACTIVE WITH SICKLE CELL DISEASE

Many people are mistaken in thinking that having sickle cell disease means they should avoid physical activity. This is not true! Exercise can actually encourage blood flow and help reduce crises or complications.

You can stay active by choosing moderate types of exercise: yoga, walking, swimming in a heated pool, volleyball, shooting basketballs, etc. Avoid heavy joint impact like you would experience on a trampoline.

Plan time to rest after exercise rest breaks every twenty minutes are a good idea. Don't forget to drink plenty of liquids, and don't push it too hard!

Listen to your body.

STREET DRUGS, TOBACCO, MARIJUANA, ALCOHOL

Stay away from these substances! They are powerfully addictive. Drugs that are inhaled or smoked are damaging to your lungs, and we know that lung problems can greatly raise your chances of sickle cell pain and acute chest syndrome. Alcohol can cause your body to become dehydrated much more easily, causing the blood cells to stick together and trigger a pain episode.

Additional notes from Dr. Lewis Hsu Dec 1, 2019: *In addition, the purity of street drugs is unknown so you never know whether there are harmful chemicals added in. For example, one chemical added to street drugs to increase the mood-altering effect is related to rat poison and can lead to uncontrolled bleeding and hospitalization.*

Vaccinations

Be sure to stay current with the vaccinations that are recommended by your doctor, starting in childhood and continuing all the way through adulthood. Vaccinations are an important protection against viral infections that can become life-threatening. The American Academy of Pediatrics strongly recommends children and adults receive vaccinations and provides a schedule for immunizations at their website as well as through the Centers for Disease Control.

Additional notes from Lewis Hsu Dec 1, 2019:

People with sickle cell have more vaccinations recommended than others. “Up to date on all your shots” for an ordinary child might not be enough protection for the child with sickle cell disease.



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DEALING WITH THE PAIN OF SICKLE CELL DISEASE

PAIN, PAIN, GO AWAY!

Sickle cell disease can cause pain. Generally, pain affects the long bones, the spine, and the ribcage. Sometimes it is an ache that is not too bad. Sometimes the pain can be more intense and needs medicine. Sometimes the pain is really too much to handle at home and you have to go to the hospital for treatment.

One way to look at different levels of sickle cell pain is to think of stairs. Pretend that more intense pain is like being higher off the ground. Pretend that climbing higher up some stairs means reaching that level of pain with more pain treatment. We can stack up pain treatments to match the intensity of the pain.



Think of your pain like stairs. Depending on your pain level, your doctors can stack different treatments to match the intensity of your pain.

WHAT CAN I DO TO PREVENT SICKLE CELL PAIN?

Unpredictable severe pain which doctors call “vaso-occlusive pain,” and which is a classic symptom of sickle cell disease, sometimes can come on without any apparent reason. Some people with sickle cell disease report an early warning sensation before the pain.

Sometimes vaso-occlusive pain can be triggered by dehydration, exhaustion, infection, low oxygen, emotional stress, change of weather or chilled skin.



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THINGS YOU CAN DO FOR YOURSELF TO HELP AVOID PAIN:


- * Take in more fluids so that you avoid dehydration. When you notice that a trigger for pain is coming along, drink more fluids!
- * Always drink more fluids when the weather changes or when the weather is very hot.
- * Avoid triggers like exhaustion from too much exercise, or exhaustion from poor sleep; get enough rest.
- * Avoid triggers such as getting chilled after swimming—get a towel and dry yourself quickly.
- * Stay current on all vaccinations/immunizations recommended by your doctor.





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TREATMENTS AT HOME


One way to remember the things you can do at home to help prevent sickle cell pain problems is the word **FARMS**:

 **Fluids.** Drinking a lot of fluids can help prevent red blood cells from sickling.

 **Air.** Get enough oxygen by taking deep breaths. Avoid conditions in which there is low oxygen, such as at high altitudes (over about 8,000 feet or about 2,500 meters). If you have asthma, be sure to treat it properly so that you do not have trouble breathing.

 **Rest, relaxation.** Take a rest break for a few minutes if you are playing or working vigorously. Build in breaks to relax if you are having a lot of emotional stress.

 **Medications, medical care.** Take medicines as prescribed by your doctors. See your doctors for regular check-ups, not just when you have pain or fever, so that problems can be detected early or even prevented. Ask questions about what else you can do to help yourself take care of your sickle cell disease.

 **Situations, support.** Avoid situations that can cause problems for your sickle cell disease: avoid getting chilled by wet clothing. Pay attention to the weather forecast and bring an umbrella if rain is likely. Friends might remind you to take a bottle of water with you when you are going out to play ball.