



## Every day matters

Live healthy with sickle cell disease

**Living with sickle cell disease (SCD) can be difficult. There can be severe pain and discomfort. Keystone VIP Choice wants to help you manage this life-threatening disease.**

**To help you stay out of the hospital, you can:**

- Avoid things that trigger a sickle cell crisis.
- Work to manage your pain.
- Know what you can do to treat your disease at home.
- Know what kind of care you can go to your doctor for and what needs emergency care.



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### Sickle cell disease (SCD)

Healthy red blood cells are round, flexible and bouncy. This helps them travel through tight spaces to carry oxygen to all parts of the body. With SCD, red blood cells become shaped like a “sickle” — like a crescent moon. Sickle cells clump together and become stuck in blood vessels. This blocks blood flow and oxygen in the body.

Those with SCD can feel tired, cranky or unable to concentrate. This is from the lack of oxygen in parts of the body. The sickle cells can also clump together in the blood vessels. This causes extreme pain. After many years, parts of the body can become damaged, including kidneys, lungs and small areas in the brain.

### Who is at the greatest risk?

Africans and African-Americans are at the greatest risk for SCD. It also affects people with Hispanic, Middle Eastern and Indian backgrounds.

SCD is genetic. Newborns are screened for SCD as a standard test at birth. Treatment can begin very early. Early treatment helps to prevent serious illness. There are medicines that can stop infection and control the symptoms of the disease. Although there is no cure for SCD, there are things you can do to help take control of your symptoms.

### Living with SCD

SCD can cause a lot of pain and discomfort. You can help prevent a “sickle cell crisis” and manage your pain.

### Avoid these triggers to prevent a sickle cell crisis:

- Cold temperatures. Going between hot and cold temperatures can cause pain or make it worse. In the winter, wear layers of clothing to keep a steady body temperature.
- Dehydration. Not drinking enough fluids may cause the blood flow to slow down. Every day, drink plenty of water and avoid caffeine.
- Infections. Wash your hands often. Avoid those who may be sick. Infections can weaken your body and may lead to an SCD crisis.
- Stress. A painful SCD crisis can come from stress. Try different ways to ease stress. Get plenty of sleep. Try calm breathing and exercise often.
- High altitude. Avoid areas of low oxygen. If you have to fly on an airplane, talk with your doctor.
- Cigarette smoke. Avoid cigarette smoke at all times. First- and second-hand smoke can cause problems in your lungs.
- Fifth disease. This is caused by a virus, often found in children. It affects red blood cells. Avoid anyone who has this disease.

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### Stay strong with SCD:

- Take folic acid. Folic acid is a B vitamin that is good for people with SCD. Ask your doctor about taking folic acid. It should be taken daily to help lower the chance of anemia (low iron).
- Get your vaccines (shots). Shots help stop many serious diseases and infections. Children and adults with SCD should get the flu shot every year. Talk with your doctor to see if you need any of your shots.
- Children up to age 5 should take penicillin. Penicillin can help stop infections. Children with SCD should take penicillin or antibiotics that fight bacteria. Talk with your doctor about penicillin for your child.
- Ask your doctor if hydroxyurea (hy-drok-see-your-ee-ah) is the right treatment choice for you or your child. Hydroxyurea helps red blood cells stay round and flexible, which may help prevent a sickle cell crisis. This medicine is recommended for children older than 9 months of age.
- Keep your hands clean. Washing your hands is one of the best ways to help stop infection.
- Eat healthy. Enjoy a healthy diet with plenty of fresh fruits and vegetables.
- Handle food safely. Be extra careful when handling raw eggs or uncooked chicken. Salmonella is very harmful to children with SCD. Make sure to wash hands. Clean all kitchen surfaces when you make and eat food.
- Watch your body temperature. Plan what you do around the weather. Dress in clothes that do not make you too hot or too cold.
- Get plenty of rest. Make sure you get enough sleep each night. Take breaks when you exercise or move around.
- Get regular checkups. Regular checkups with your doctor can help stop some serious problems. Always take medicine and vitamins as your doctor tells you.
- Get support. Find an SCD support group in your area. Talk with a close family member, friend or health care professional. You can also join groups at your local church or in your faith-based community.



## Treating a sickle cell crisis

Make sure you know what can be treated at home and what needs emergency care. Talk to your doctor about the symptoms of a sickle cell event before they happen. Having a plan is important if you need care right away.

### Home treatment:

- Take warm baths or showers. This can help move the blood flow.
- Put a heating pad where you have pain. Never use ice or cold packs. This could make pain worse.
- Drink more liquids, such as water or juice. Drink 8 to 10 glasses of water every day.
- Don't eat or drink anything with caffeine. Caffeine limits blood flow in the body.
- Massage. It may feel good to gently massage the area that hurts. Relax to ease the pain.

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If you think you have an emergency, call 9-1-1.

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## Signs of an emergency

These symptoms always need immediate medical care. They often mean that the problems you are having are serious and sometimes life-threatening. If you have any of these symptoms, call your doctor right away!

- A fever over 101°F. This might mean you have an infection. Other signs of infection can be chills, feeling irritable and vomiting.
- Severe pain, especially in hands, feet, chest and belly. Chest pain can cause trouble breathing.
- Drooling, weakness, confusion, or sudden trouble with speaking or walking. These could be signs of a stroke.
- A very long, unwanted and painful erection of the penis.
- Jaundice or yellowing of the skin, eyes and mouth.

## Describe your symptoms

It is very important you tell your doctor about your symptoms. No one else can feel what you are feeling. Your doctor will tell you what you need to do.

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## What you need to tell your doctor:

- Try to rate your pain using the 0 –10 pain scale, 10 being the worst pain.
- Describe the pain — for example, aching, throbbing or sharp.
- Describe where you have pain.
- Tell how long you have had the pain.
- Talk about what makes your pain feel better.

Living with SCD can be difficult. But there are ways to manage pain and prevent a crisis. Keystone VIP Choice wants to help keep you out of the emergency room because every day matters. Know what can be treated at home and what needs emergency care.

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## If you have any questions, we can help. Remember these important numbers.

### Member Services

1-800-450-1166

### 24-Hour Nurse Call Line

1-888-765-6375

### Rapid Response and Outreach Team

1-855-809-9203

### Emergency

9-1-1

Your doctor: \_\_\_\_\_



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Keystone VIP Choice is a HMO-SNP plan with a Medicare contract and a contract with the Pennsylvania Medicaid program. Enrollment in Keystone VIP Choice depends on Medicare Contract renewal.

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