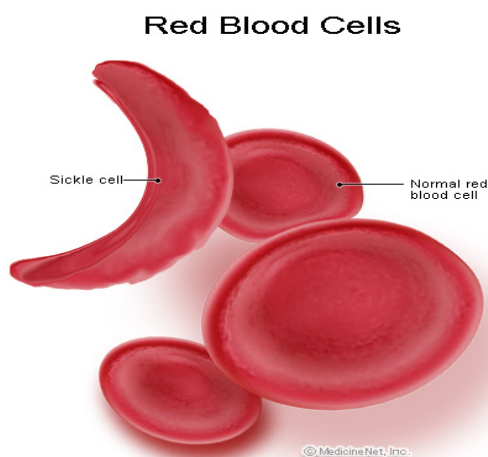


SICKLE CELL ANEMIA SUPPORT BOOKLET

“Do what you can, with what you have, where you are.”
Theodore Roosevelt

WHAT IS SICKLE CELL DISEASE?

Sickle cell anemia is an inherited disease that affects the red blood cells. It is a life-long disease that will affect many areas of your life. This disease is inherited from your parents and can be passed to your children. If one parent has the disease and one does not, then their children will have a condition called “sickle cell trait” and are carriers of the disease. “Over 50,000 black Americans suffer from sickle cell disease, which makes it a major public health concern in the United States,” writes Miriam Bloom, PhD- a geneticist and former senior editor of the Journal of the National Cancer Institute. In sickle cell disease, abnormal hemoglobin (Hemoglobin S) is produced, which causes the red blood cells to twist. The result: the soft, round red blood cells become stiff and crescent-shaped (like a sickle used to cut wheat). These cells tend to pile up and stick together in the blood vessels. This can cause reduced blood flow and oxygen supply to the body, and believed to be the cause of the pain crisis.



HOW DOES THE BODY GET THE OXYGEN IT NEEDS?

Using a protein called hemoglobin, red blood cells carry oxygen to all parts of the body.

Facts about normal red blood cells:

- Normal cells live for 120 days.
- Old normal cells die, but new ones are continually made by the body.
- Normal cells are flexible and soft- moving easily through blood vessels.

Facts about sickle cells:

- Sickle cells live only 10-20 days.
- Sickle cells become stiff and stick together- they do not together, become stiff and stick to each other- they do not move easily through blood vessels.
- Sickle cells stick together and block blood flow. This reduces the oxygen supply to the body. This lack of oxygen causes the swelling and pain in the tissue, muscles, and joints.

WHAT INSTRUCTIONS CAN I FOLLOW AT HOME?

Follow up with your primary care physician. If you do not have a physician, the hospital Social Worker can provide phone numbers for other choices and alternatives. The Health Department is located at 3241 Lakeland Hills Blvd in Lakeland; phone number (863) 413-2620. Call or make an appointment with your healthcare provider if you experience any of the following:

Fever	Unusual headaches	Chest pain
Shortness of breath	Increased tenderness	Pain that won't go away
Painful prolonged erection	Sudden changes in vision	Abdominal swelling

WHAT ARE THE COMMON COMPLICATIONS OF SICKLE CELL DISEASE?

Painful crisis	Infections	Skin ulcers
Strokes	Vision problems	Gall stones
Heart disease		

WHAT ARE SOME RECOMMENDATIONS FOR GENERAL HEALTH?

1. Nutrition and Hydration:
 - Follow a healthy eating plan: eat foods high in protein, vitamins B6, B12, and folic acid. Folic acid every day will help the body make new red blood cells.
 - Remember that extra calories give energy and helps ward off infections. Some recommendations of food rich in these are: fresh meats, trout and salmon, poultry, whole grains (such as breads, cereals, oats, and barley), avocados, potatoes with skin, watermelon, bananas, and nuts.
 - Remember to eat foods rich in antioxidants: the skins of fruits and vegetables, and bright and dark colored fruits and vegetables, including sweet potatoes, carrots, spinach, cantaloupe, mangos, red and green peppers, beets, papayas and blueberries.
 - To prevent dehydration, you should drink at least 8 glasses of water daily, especially in warm weather. Preferred is 1-3 liters a day, depending on advice from your physician.
2. Obtain regular blood tests to check your hemoglobin and iron levels. These test results will tell if you are dehydrated and need extra fluids.

3. Ask about the flu and pneumonia vaccine. You can get these from your physician and the Health Department. During flu season, Publix and Walgreens offer vaccines (the flu vaccine cost ranges from free- \$25; the pneumonia vaccine costs ranges from \$25-\$45)
4. Have an annual screen for TB (Tuberculosis).
5. Have regular vision examinations.
6. Avoid alcohol and use of recreational drugs.
7. Stop smoking: *This is important because smoking constricts the already injured blood vessels.* (www.stopsmoking.net is a helpful site.)
8. The body needs regular physical activity, however you should avoid exercise that makes you very tired or short of breath. Rest and sleep is crucial, the people with sickle cell anemia are more susceptible for sleep apnea. You should tell your physician about snoring or sleep apnea.

WHAT ARE SOME STEPS TO PREVENT AND CONTROL SICKLE CELL COMPLICATIONS?

1. Avoid decongestants, these medications can tighten blood vessels and further prevent red blood cells from moving smoothly through the vessels. The only over the counter decongestants available in pill form are pseudoephedrine (Contac non-drowsy and Sudafed) and phenylephrine (Sudafed PE). Some over the counter nasal sprays also contain decongestants and should only be used for 3 days.
2. Avoid extremes of heat and cold. Wear warm clothes outside in cold weather and inside in air-conditioned rooms. Don't swim in cold water or climb at high altitudes without extra oxygen.
3. Reduce stress in your life. Seek support from physician, family and friends, as well as a support group to cope with daily life. The available web sites are listed in this booklet.
4. Avoid jobs that require a lot of physical labor or long hours.
5. Don't travel in airplanes where the cabins aren't pressurized, as this causes blood vessels to constrict.
6. See your dentist regularly to prevent tooth decay and loss of teeth.
7. Learn the signs and symptoms of stroke: a lasting headache; weakness on one side of the body; limping and/or sudden changes in speech, vision or hearing. Report promptly to a local emergency room or call for an ambulance if needed.
8. Women will need special prenatal care as the disease can worsen during pregnancy. Women with sickle cell also are at increased risk for early birth or low birth weight babies. With early prenatal care, she can have a healthy pregnancy. Learn ways to cope with and manage pain.

9. Your doctor may prescribe narcotic pain medicines and you may need over the counter analgesics. Use these medications safely. Other ways to manage pain may include a heating pad (use safety recommendations from manufacturer), massage (ask a family member or friend), taking a **warm** bath or resting. Physical therapy and exercise might help ease pain by helping you relax and strengthening the muscles and joints. Counseling or self-hypnosis also may help. You may find that activities that keep you mind off the pain, such as watching TV, chatting on the computer, or phone conversations are helpful.

SICKLE CELL DISEASE (SCD) FORUMS AND WEBSITES

People who lead a lonely existence always have something on their minds that they are eager to talk about.

-Anton Checkov

Anyone living with a chronic illness faces hurdles in both health and life. Each of these websites promotes enhanced personal care and decision-making skills, and provides a network of peer-to peer support. You can link to resources; services and programs; events; on-line educational videos and materials; SCD chat rooms; free counseling; and sharing of knowledge to improve quality of life.

- *American Sickle Cell Anemia Association*: This organization has a children’s forum- CHAMPPS.

Website: www.ascaa.org/

Phone: 216-229-8600

- *Sickle Cell Disease Association of America*: This organization can be followed on Facebook and twitter, and offers various educational opportunities, links, and an online store.

Website: www.sicklecelldisease.org/

Phone toll free: 1-800-421-8453

- *The Sickle Cell Foundation of Georgia, Inc.*: This organization’s mission is to “Break the Sickle Cell Cycle through Knowledge, Help and Hope;” they offer a children’s summer camp and a downloadable tutorial on SCD.

Website: www.sicklecellGa.org/

Phone: (404) 755-1641

- *Sickle Cell Society, Inc.*: This organization has information on the medical, psychosocial, and educational parts of living with SCD.

Website: www.sicklecellsociety.org/

Phone: 412-371-0628

- *Sickle Cell Forum*: This is an online support group that “encourages open discussions about what is working and not working” for people who live with SCD.

Website: <http://healthgroups.yahoo.com/group/sicklecell>.

- *Sickle Cell Foundation of Hillsborough and Polk Counties*: This organization offers education and support about SCD. They are located at the Lee Davis Neighborhood Center in Tampa.

Phone: 813-247-5999 for Mrs. Sandra Owens, Outreach Coordinator

SICKLE CELL DISEASE (SCD) BOOKS (available on Amazon.com)

Allen F. Platt and Alan Sacerdote; *A Patient’s and Parent’s Guide to Sickle Cell Anemia* (2006).

Miriam Bloom; *Understanding Sickle Cell Disease* (1995).

Ola Tamedu; *Menace in My Blood: My Affliction with Sickle Cell Anemia* (2006).

r.m. Reid; *Our Little Blessing: A Story About Sickle Cell Disease* (2008).

Evidence-based Resources

Banerjee, S., & Chopra, S. (2009, February 20). *Hepatic manifestations of sickle cell disease*. Retrieved September 23, 2009, from http://www.utdol.com/online/content/topic.do?topicKey=hep_dis/1904&selectedTitle=12

Gorman, K., (1999). Sickle cell disease: Do you doubt your patient’s pain?. *American Journal of Nursing*, 99, 38-44.

McCrae, J. D., & Lumley, M. A. (1998). Health status in sickle cell disease: Examining the roles of pain coping strategies, somatic awareness and negative affectivity. *Journal of Behavioral Medicine*, 21, 35-55.

Midence, K., Graham, V., Acheampong, C., & Okuyiga, E. (1997).

Increasing awareness for higher quality care: Measuring knowledge of sickle cell disease in adult patients. *Professional Nurse*, 9, 255-258.

Ohaeri, J. U., Shokunbi, W. A., Akinlade, K. S., & Dare, L. O. (2000). The psychosocial problems of sickle cell disease sufferers and their methods of coping. *Social Science Medicine*, 40, 955-960.

Rosse, W. F., Gallagher, D., & Kinney, T. R. (2007). Transfusion and alloimmunization in sickle cell disease. *New England Journal of Medicine*, 314, 1593-1599.

Silliman, C. C., Peterson, V. M., & Mellman, D. L. (1998). Iron chelation by deferoxamine in sickle cell patients with severe transfusion-induced hemosiderosis: A randomized, double-blind study of the dose-response relationship. *Journal of Laboratory and Clinical Medicine.*, 122(48), 767-789.

Todd, K. H. (2006). Sickle cell disease related pain: Crisis and conflict. *Journal of Pain Management*, 7(7), 453-458.

Wong, W. Y. (2005). Overt and complete (silent) cerebral infarction in sickle cell anemia: Diagnosis and management. *Hematology Oncology Journal of North America*, 19(5), 839-855.