



Sickle Cell Rapper

The Children's Regional Sickle Cell Center—San Antonio, TX

Winter 2005

Doctor's Corner—Winter and Sickle Cell

As the winter months approach, even in San Antonio, it is important that we take precautions to minimize the number of pain crisis in our sickle cell patients. Everyone should get the Flu shot, but additional triggers for sickling crisis include dehydration, over exertion and extreme weather changes.

Dehydration: Dr. Hsu suggests that simple maintenance of good hydration (drinking plenty of fluids) slows the sickling process by 1700 percent. Dehydration not only impacts the red cells, but also damages multiple organ systems, most importantly the kidneys. Kidney damage will lead to increase urine loss and thus worsening dehydration. Dehydration, even in the winter can be caused by excess sweating, vomiting and diarrhea, increased urination and doctor's request to fluid restriction of sickle cell patients prior to surgery.

Type of fluids to drink include, water, milk, fruit juices, sports drinks. Avoid drinks containing caffeine such as sodas, coffee, tea and alcohol. Sorry kids!

Over Exertion: *Dr. Moore, can I run cross country, play basketball or swim five miles a day?*

Under most circumstances we encourage good physical activity. Sickle Cell Anemia does not mean you can be a "couch potato". We do, however, have to use certain precautions and monitor ourselves for potential problems from over-exertion. Too much exercise can lead to lactic acidosis, especially when you are already anemic. Acidosis triggers sickling and sickling triggers pain crises. Rules to follow:

Maintain adequate hydration

Rest—allow 15-20 minutes rest periods between most physical activities to allow the body to recover. (In basketball, play the first and third quarter rather than attempting to play the entire game.)

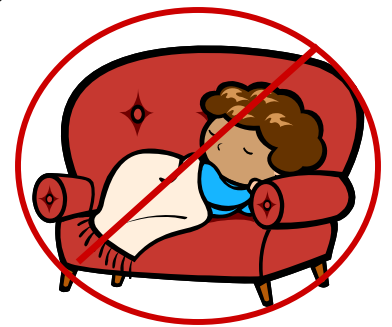
As a sickle cell patient, you are your best gauge for physical activity. If it hurts—STOP!

Extreme Changes in Temperature can trigger sickling and thus pain crises, even in San Antonio when the temperature has been in the 80's and suddenly drops to the 40's and 50's this may cause more sickling. Cold weather causes blood vessels to shrink and therefore lead to increased blockage of the vessels and pain crisis. Cold weather also causes moderate use of oxygen by the muscles and possible acidosis. No, this does not mean that you can skip school from December to February; however, you must dress warmly to avoid these sickling crises. Again, stay hydrated. For those sicklers who just have to swim—avoid jumping in cold pools. Heated pools only. On cold days, stay in a warm environment as much as possible. In the next Sickle Cell Rapper: Can Sickle Cell Disease be cured—bone marrow transplantation.

Reginald Moore, MD

Medical Director

The Children's Regional Sickle Cell Center



How Can Psychology Help?

The pain associated with sickle cell disease can affect your life in many different ways. It may disrupt sleep, reduce energy, interfere with school or work, and restrict your social activities. It may have a negative impact on a family's financial security, and it may cause a strain on family relationships. Because no one can see pain, people who experience severe pain often feel alone in their suffering. Some may feel that no one even believes that their pain is real. Given the impact that pain can have on quality of life, it is no surprise that many people who experience frequent pain crises also experience depression or anxiety.

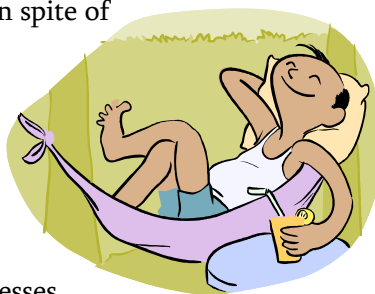
It may be beneficial for people with sickle cell disease to see a psychologist, social worker, or psychiatrist to get help coping with the illness. It can also be helpful for family members of sickle cell patients to speak with a psychologist about the stress and frustration they may feel. Psychologists

use various techniques to help patients improve the quality of their lives in spite of

the pain. For example, psychologists can help patients learn relaxation techniques, which can improve coping with pain and illness. They may also use other techniques such as distraction, stress management, problem solving, and assertiveness training. Finally, psychotherapy or counseling

for depression and anxiety is often helpful in managing the emotional

consequences of pain and chronic illness. In fact, people with chronic illnesses are often treated in group therapy where they are able to share their experiences with others who live with the same disease.



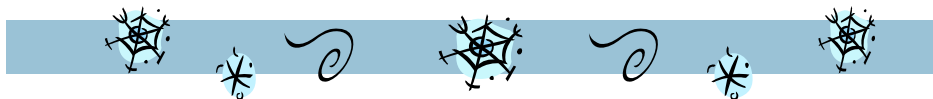
Psychological techniques and approaches have been proven to help people with pain improve the quality of their lives. Patients report that they are more active, less depressed and anxious, and feel more in control. Even though they continue to have pain, it becomes more manageable and interferes less with their daily lives.

If you would like to speak with a psychologist at our clinic, please contact Dr. Leanne Embry Segovia at (210) 704-2987, or Dr. Beneza Marquez at (210) 704-2853. We are here to help!

Leanne Embry Segovia, Ph.D.

Licensed Psychologist

Britton Children's Cancer and Blood Disorders Center



Before you go to the ER ...

Going to the Emergency Room can be a very scary experience. In order for us to help you, we need to know you are coming. Please, before any ER trip, call

210-704-2011

ask for the Pediatric Hematologist On Call

This is especially important if you are **16 years or older**. It will help us prepare for your arrival and ensure you are routed properly.



When to Refill Your Prescription

In order to serve you best, please remember these tips when you need to refill your prescription.

- Call ahead of time, call us when you have one week's supply left. This will ensure that you receive your prescription on time. Remember, the clinic isn't open over the weekend, so call early!
- When calling, have your medication handy. This will help us to correctly refill your prescription.

Call 704-2187 & Press # 5 for refills




Sickle Cell Kids Corner— WARNING



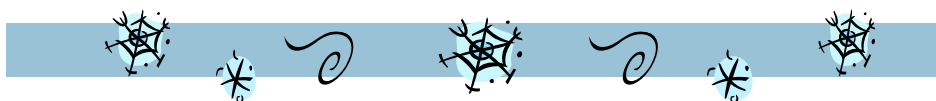
If you have any of these symptoms — tell a grownup **FAST!!**

- Fever over 101
- Chest pain
- Hard to breathe
- Getting more and more tired
- Abdominal swelling
- A headache that’s different from usual
- Any sudden weakness or loss of feeling
- Pain that won’t go away with home treatment
- Sudden change in vision

To Avoid Problems Remember—F A R M S

| | | |
|---|-----------------------------|--|
| F | FEVER FLUIDSFOODS | Tell a grownup if you feel warm. Drink plenty of fluids each day. (Water is best). Eat a healthy balanced diet.  |
| A | AIR | Be careful in situations where you might not get enough oxygen. |
| R | REST | Get plenty of sleep each night. Don’t overdo it. Take a break whenever you feel tired. |
| M | MEDICATIONS MEDICAL CARE | Always take your medicine and vitamins. Get proper medical care. |
| S | SITUATIONS | Be aware of certain situations: Don’t get too hot or too cold Avoid getting too tired or upset If you go outside to play, wear clothes for the season and take plenty of water—Pace yourself when you play. |

Elisa Ornelas, LSW
Social Worker
UTHSCSA – Dept .of Pediatrics Hem/Onc



Spotlight — Ms. Donna Doulton



We would like to introduce you to Ms. Donna Doulton. She has been working very closely with our Sickle Cell patients scheduling appointments and answering any questions. Please take a moment to get to know her.

Ms. Doulton is from an isolated northern community of Port Cartier, in the province of Quebec, Canada. She graduated from the diploma program at John Abbot College in Ste. Anne-de-Bellevue, Quebec, Canada. She graduated in 1993 with Baccalaureate of Science in Nursing from University of Ottawa, Ottawa, Ontario, Canada.

She started her nursing career with Montreal Children's Hospital in June 1985 working with Burns & Neurology. Ms. Doulton then transferred in 1986 to Pediatric Hematology/Oncology and over the years has worked with Sickle Cell, Bone Marrow Transplants, Palliative Care. From 1994 to 1997 she transferred to an outpatient clinic in Pediatric Hematology/Oncology, becoming the Sickle Cell Nurse. Since 1997 she has been working on the 8th floor of Christus Santa Rosa Children's Hospital with Pediatric Hematology/Oncology.

At present she works every Tuesday & Wednesday from 8:30 - 5:00 p.m.. If she not available please leave a message for her & she will contact you as soon as possible. 1-800-227-3618





Medical Director

Reginald Moore, MD

Hematologists/Oncologists

Anne-Marie Langevin, MD

Howard A. Britton, MD, FAAP

Paul J. Thomas, MD, FAAP

Javier R. Kane, MD

Shafqat Shah, MD

Shannon Carpenter, MD

Immunologist

Anthony Infante, MD, PhD

Psychologist

Leanne Embry, PhD

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