

Living Well With Sickle Cell Disease Self-Care Toolkit



National Center on Birth Defects and Developmental Disabilities
Division of Blood Disorders





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INTRODUCTION

What Is the Living Well With Sickle Cell Disease: Self-Care Toolkit?

A toolkit is a collection of materials that can be used to help you to manage your health and keep track of important information regarding sickle cell disease (SCD). The Living Well With Sickle Cell Disease: Self-Care Toolkit has multiple uses. It is designed to help you and your caregivers with management of your disease, medical care, services, and health providers. The toolkit also will help communication between the many health providers and service providers that are involved with patient care.

Why Should I Use the Living Well With Sickle Cell Disease: Self-Care Toolkit?

Because many doctors are not familiar with SCD, it is very important for you to take an active role in managing your own care. To make important decisions, you need to know about SCD, understand your treatment options, and then make the best possible choices for your health. Using the tools provided in this toolkit will help you to monitor your health care and manage your disease. Putting together a care notebook or binder that you can take with you wherever and whenever (for example doctor's appointments, emergency room visits, vacation, and the workplace) you need it will help you organize all of your SCD-related medical information in one place so that you can keep track of information over time.

You might want to include the following:

- Doctor contact information.
- Medical appointments.
- Changes in medications or treatments.
- Test results.
- Vaccination and immunization (shots) records.
- Community resources.
- Any other information about your condition (facts found on the Internet, in brochures, and from any other sources of information and support).

By organizing all of your SCD-related information in one place, you can:

- Actively take part in, and advocate for, your own care.
- Work together with the doctors on your medical team.
- Remember new and complex information that is hard to process (when the doctor first tells you about a condition, if the condition worsens, or when treatment changes).
- If you are a teenager or young adult with SCD, you can begin to take responsibility for your own health history and information.



Section 1:

Sickle Cell Disease 101

What Is Sickle Cell Disease?

Sickle cell disease (SCD) is a group of inherited red blood cell disorders.

- Healthy red blood cells are round and they move through small blood vessels carrying oxygen to all parts of the body.
- For someone with SCD, the red blood cells become hard and sticky and look like a C-shaped farm tool called a “sickle”.
- Sickle cells die early in comparison to non- sickle cells, which causes a constant shortage of red blood cells.
- Sickle cells can get stuck in small blood vessels and block the flow of blood and oxygen to organs in the body. These changes in cells can cause repeated episodes of severe pain, organ damage, serious infections, or even stroke.

What Causes Sickle Cell Disease?

SCD is inherited in the same way that people get the color of their eyes, skin, and hair.

- A person with SCD is born with it.
- People cannot “catch” SCD from being around a person who has it.

Who Is Affected by Sickle Cell Disease?

- It is estimated that SCD affects 90,000 to 100,000 people in the United States, mainly Blacks or African Americans.
- The disease occurs among about 1 of every 500 Black or African-American births and among about 1 of every 36,000 Hispanic-American births.
- SCD affects millions of people throughout the world and is particularly common among those whose ancestors come from sub-Saharan Africa; regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy.



What Health Problems Does Sickle Cell Disease Cause?

The following are some of the most common complications of SCD:

Pain Episodes or Crises—Sickle cells don't move easily through small blood vessels and can get stuck and clog blood flow. This causes pain that can start suddenly, be mild to severe, and last for any length of time.

Infection—People with SCD, especially infants and children, are more likely to experience harmful infections such as influenza, meningitis (infection of the brain or spinal cord), and hepatitis (infection of the liver).

Hand-Foot Syndrome—Swelling in the hands and feet, often along with a fever, is caused by the sickle cells getting stuck in the blood vessels and blocking the blood from flowing freely through the hands and feet.

Eye Disease—SCD can affect the blood vessels in the eye and lead to long-term damage.

Acute Chest Syndrome—Blockage of the flow of blood to the lungs can cause acute chest syndrome (ACS). ACS is similar to pneumonia; symptoms include but are not limited to chest pain, coughing, difficulty breathing, and fever. It can be life threatening and should be treated in a hospital.

Stroke—Sickle cells can clog blood flow to the brain and cause a stroke. A stroke can result in lifelong disabilities and learning problems.

How Is Sickle Cell Disease Treated?

The goals of treating SCD are to relieve pain and to prevent infections, eye damage, and strokes. There is no single best treatment for all people with SCD. Treatment options are different for each person depending on the symptoms. Treatments can include receiving blood transfusions, receiving intravenous therapy (fluids given into a vein), and medications to help with pain.

- For severe SCD, a medicine called hydroxyurea might be recommended. Research suggests that hydroxyurea can reduce the number of painful episodes and the recurrence of ACS. It also can reduce hospital stays and the need for blood transfusions among adults who have SCD.

Is There a Cure for Sickle Cell Disease?

To date, the only cure for SCD is a bone marrow or stem cell transplant.

- A bone marrow or stem cell transplant is a procedure that takes healthy stem cells from a donor and puts them into someone whose bone marrow is not working properly. These healthy stem cells cause the bone marrow to make new, healthy cells.
- Bone marrow or stem cell transplants are very risky, and can have serious side effects, including death. For the transplant to work, the bone marrow must be a close match.



Section 2:

Living Well With Sickle Cell Disease

Six Steps to Living Well With Sickle Cell Disease

You can live a full life and enjoy most of the activities that other people do. The following tips will help you stay as healthy as possible:

Find good medical care—Sickle cell disease is a complex disease. Good quality medical care from doctors and nurses who know a lot about the disease can help prevent some serious problems. Often, the best choice is a hematologist (a doctor who specializes in blood diseases) working with a team of specialists.

Get regular checkups—Regular health checkups with a primary care doctor can help prevent some serious problems.

Prevent infections—Common illnesses, like influenza, quickly can become dangerous for a person with SCD. The best defense is to take simple steps like washing your hands frequently to help prevent infections. See “Five Tips to Help Prevent Infection” for more information.

Learn healthy habits—Drinking 8 to 10 glasses of water every day and eating healthy food will help to maintain hydration and proper nutrition. People with SCD should maintain a balanced body temperature, getting neither too hot nor too cold. Participating in physical activity to help stay healthy is very important. However, it’s essential that you don’t overdo it, rest when tired, and drink plenty of water.

Look for clinical studies—New clinical research studies occur frequently and these studies might give you access to new medicines and treatment options.

Get support—Find a patient support group or community-based organization that can provide information, assistance, and support.



Five Tips To Help Prevent Infections

Common illnesses, like influenza quickly can become dangerous for a person with SCD.

The best defense is to take simple steps to help prevent infections.

1. **Vaccines**—Vaccines are a great way to prevent many serious infections. Adults and children with SCD should have the influenza vaccine every year, as well as the pneumococcal vaccine and any others recommended by their doctor.
2. **Penicillin**—Penicillin can help prevent infections. Children with SCD should take penicillin (or another antibiotic prescribed by a doctor) every day until they are at least 5 years of age.
3. **Washing hands**—Washing your hands is one of the best ways to help prevent getting an infection. People with SCD, their families, and other caretakers should wash their hands with soap and clean water many times each day. If you don't have access to soap and water, you can use gel hand cleaners with alcohol in them.

Wash your hands before

- Making food.
- Eating.

Wash your hands after

- Using the bathroom.
 - Blowing your nose, coughing, or sneezing.
 - Shaking hands.
 - Touching people or things that can carry germs, such as:
 - » Diapers or a child who has used the toilet.
 - » Food that has not been cooked (raw meat, raw eggs, or unwashed vegetables).
 - » Animals or animal waste.
 - » Trash.
 - » A person who is sick.
4. **Food Safety**—Salmonella, a type of bacterium in some foods, can be especially harmful to children with SCD. To avoid exposure to this and other bacteria and to stay safe when cooking and eating:
 - Wash your hands, cutting boards, counters, knives, and other utensils after they touch uncooked foods.
 - Wash vegetables and fruit well before eating them.
 - Cook meat until it's well done. The juices should run clear and there should be no pink inside.



- Do not eat raw or undercooked eggs. Raw eggs might be “hiding” in homemade hollandaise sauce, Caesar and other homemade salad dressings, tiramisu, homemade ice cream, homemade mayonnaise, cookie dough, and frostings.
 - Do not eat raw or unpasteurized milk or other dairy products (cheeses). Make sure these foods have a label that says they are “pasteurized”.
5. **Avoid Reptiles**—Salmonella (mentioned previously) is present in some reptiles and can be especially harmful to people with SCD. Make sure children and adults stay away from turtles, snakes, and lizards.

Emergency Guide: When To See the Doctor

It is very important that every person with SCD have a plan for how to get help immediately—at any hour—if there is a problem. Be sure to find a medical facility that will have access to your medical records or keep a copy that you can bring.

Go to an emergency room or urgent care facility *right away* for:

- Fever above 101°F.
- Difficulty breathing.
- Chest pain.
- Abdominal (belly) swelling.
- Severe headache.
- Sudden weakness or loss of feeling and movement.
- Seizure.
- Painful erection of the penis that lasts more than 4 hours.

Call a doctor *right away* for:

- Pain anywhere in the body that will not go away with treatment at home.
- Any sudden problem with vision.



Coping With Stress

The Basics

Preventing and managing stress can help lower your risk of serious health problems associated with SCD. You can prevent or lessen stress by:

- Planning ahead.
- Preparing for stressful events.

Some stress is hard to avoid. You can find ways to manage stress by:

- Recognizing when you feel stressed.
- Taking time to relax.
- Getting active and eating healthy.
- Sharing your feelings with friends and family.

What Are the Signs of Stress?

When people are under stress, they might feel:

- Worried.
- Irritable.
- Depressed.
- Unable to focus.

Stress also affects the body. Physical signs of stress include:

- Headaches.
- Back pain.
- Problems sleeping.
- Stomach upset.
- Weight gain or loss.
- Tense muscles.
- Frequent or more serious colds.



What Causes Stress?

Stress often is caused by some type of change. Even positive changes, like marriage or a job promotion, can be stressful. Stress can be short term or long term.

Common Causes of Short-Term Stress

- Having too much to do and not much time.
- Having lots of little problems on the same day (like encountering a traffic jam or running late).
- Getting lost.
- Having an argument.

Common Causes of Longer Term Stress

- Relationship issues.
- Death of a loved one.
- Illness.
- Caring for someone who is sick.
- Problems at work.
- Money problems.

What are the benefits of managing stress?

Managing stress can help you:

- Sleep better.
- Control your weight.
- Get sick less often and heal faster.
- Lessen neck and back pain.
- Be in a better mood.
- Get along better with family and friends

Take Action!

Being prepared and in control of your condition will help you feel less stress. Follow these six tips to prevent and manage stress.

Plan your time—Think ahead about how you are going to use your time. Write a to-do list and decide which tasks are the most important. Be realistic about how long each task will take.

Relax with deep breathing—Take part in deep breathing activities or yoga classes.



Relax your muscles—Try stretching or taking a hot shower to help you relax. Stress causes tension in your muscles.

Get moving—Plan physical activity to help prevent and manage stress. It also can help relax your muscles and improve your mood. Before you start, be sure to discuss any new exercise routine with your doctor.

- Aim for 2 hours and 30 minutes a week of moderate aerobic activity (e.g. walking or biking).
- Be sure to exercise for at least 10 minutes at a time.
- Do strengthening activities (like sit-ups or lifting weights) at least 2 days a week.

Share your feelings with friends and family—Tell your friends and family if you are feeling stressed. They might be able to help.

Get help if you need it—Find help if your stress doesn't go away or keeps getting worse.

Fifteen Reasons Why Exercise Is Good

Being physically active can help with maintaining overall good health. The following are examples of the benefits of exercising:

- ✓ Helps to improve and maintain good overall health.
- ✓ Strengthens the cardiovascular system—heart, lungs and blood vessels
- ✓ Reduces the risk of persistent illness.
- ✓ Increases muscle strength.
- ✓ Improves flexibility.
- ✓ Increases endurance and stamina.
- ✓ Increases natural pain killers (called endorphins) in the body's nervous system, which help control pain.
- ✓ Helps with weight control.
- ✓ Helps to improve quality of sleep.
- ✓ Helps balance and coordination.
- ✓ Reduces fatigue and increases energy.
- ✓ Reduces muscular tension, stress, and depression.
- ✓ Helps combat depression and anxiety.
- ✓ Helps you maintain a positive outlook.
- ✓ Helps to prevent constipation.



Section 3: Tools for Managing Your Health

Where Can I Find and Print the Forms for My Self-Care Toolkit?

The Living Well With Sickle Cell Disease: Self-Care Toolkit includes several forms that you can use to keep track of important information, manage your health, and monitor your medical care. You can print copies of these forms, which are available at <http://www.cdc.gov/ncbddd/sicklecell/index.html>.

How Often Should I Update the Information in My Self-Care Toolkit?

To be most helpful, your Self-Care Toolkit should provide a snapshot of your current health status. Be sure to include new prescriptions and treatment information. Once every few months, you might want to go through your toolkit and remove or file certain sections if they are getting too large or you find you no longer need them.

Who Should Know About My Self-Care Toolkit?

You should make sure that a family member or other caregiver knows that you have a Self-Care Toolkit. You also should make sure that they can find it in an emergency and bring it to the clinic or hospital where you are receiving care.



FORMS



DEVELOPING S.M.A.R.T GOALS

S Clearly define desired outcome Example: Lose 20 pounds	M measurable Define goals by numbers Example: Progress can be shown by weekly weigh-in	A attainable Create goals that motivate Example: I will increase my exercise to 4 times per week	R realistic Set challenging but realistic goals Example: I will cut back on sugary foods	T time-frame Set deadlines for accomplishments Example: Lose 2 pounds per week for 10 weeks
Long-Term ultimate goal				
1				
2				
3				
4				

Short-Term
stepping stones



HEALTHY BEHAVIOR CONTRACT

Use the goals developed on the Developing S.M.A.R.T Goals form to complete your healthy behavior contract. Use this contract to help you to set and attain healthy behaviors that will improve your health and well-being.

Based on an awareness of my health status, I, _____
have decided to set the following behavior-related health goal, which will contribute to improvement of my personal well-being.

My health behavior goal is: _____

(long-term SMART goal)

The benefits of my achieving this goal are: _____

The anticipated problems or barriers to taking positive action are: _____

The behaviors I will adopt to accomplish this personal health goal are: _____

(short-term SMART goal)

I will reinforce my actions by: _____
and reward achievement of my goal by _____

I, _____, have reviewed this contract and agree to be a part of a positive support system throughout this behavior change project.

Signed _____ Date _____

I have reviewed this contract and agree to take action to accomplish my goal and to discuss the results with my provider, family member or friend. Upon completion of this contract, I will identify my next area of opportunity and take further steps to improve my health status.

Signed _____ Date _____

Witness _____ Date _____

Provider/Family Member/Friend



PERSONAL/FAMILY INFORMATION SHEET

Use this form to record personal and family information in case of an emergency.

YOUR NAME:	
DATE OF BIRTH:	
DIAGNOSIS:	
BLOOD TYPE:	
ADDRESS:	
TELEPHONE NUMBER:	

PARENT NAME (IF APPLICABLE):	
ADDRESS:	
TELEPHONE NUMBER:	

ADDITIONAL FAMILY INFORMATION

LANGUAGE SPOKEN AT HOME:		
OTHER LANGUAGE(S):		
INTERPRETER NEEDED (CIRCLE YES OR NO):	Yes	No



MEDICAL EMERGENCY INFORMATION SHEET

Use this form to maintain correct medical information the case of an emergency.

PERSONAL INFORMATION				
Last Name		First Name		Middle Initial
Date of Birth	Sex	Weight	Blood Type	
Address				
City		State	Zip Code	
Primary Insurance		Secondary Insurance		
Primary Insurance Numbers & Group		Secondary Insurance Numbers & Group		

SICKLE CELL DISEASE (TYPE)
<input type="checkbox"/> SS (sickle cell anemia)
<input type="checkbox"/> SC (sickle cell hemoglobin C)
<input type="checkbox"/> S Beta Thalassemia
Other _____

ALLERGIES	CARDIAC	SURGERY
<input type="checkbox"/> None <input type="checkbox"/> Unknown Medical Allergies: _____ _____ _____ _____ _____	<input type="checkbox"/> None <input type="checkbox"/> Unknown <input type="checkbox"/> Angina <input type="checkbox"/> Arrhythmia <input type="checkbox"/> Congestive Heart Failure <input type="checkbox"/> Congenital <input type="checkbox"/> MI _____ Other _____ _____	<input type="checkbox"/> None <input type="checkbox"/> Unknown <input type="checkbox"/> Abdominal <input type="checkbox"/> Heart <input type="checkbox"/> Lung <input type="checkbox"/> Neurological Other _____ _____ _____



OTHER CHRONIC CONDITIONS

- None
- Asthma
- Bleeding Disorder
- Cancer
- Diabetic

- Gastrointestinal
- Headaches
- Hepatitis
- HIV +
- Hypertension
- Paralysis

- Psychological
- Seizures
- Substance Abuse
- TB
- Unknown
- Other _____
- _____

CURRENT MEDICATIONS

- None
- Unknown

EMERGENCY CONTACT INFORMATION

Primary Physician:	Physician Telephone Number:
Primary Contact Name & Relationship:	Primary Contact Telephone Numbers:
Secondary Contact Name & Relationship:	Secondary Contact Telephone Numbers:

Update information regularly! Use a separate sheet for additional information.



SPECIALTY CARE INFORMATION SHEET

Use this form to keep track of the specialty providers who are part of your medical treatment team.

SPECIALTY CARE PROVIDER:	
DATE OF 1ST VISIT:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	
COMMENTS:	

SPECIALTY CARE PROVIDER:	
DATE OF 1ST VISIT:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	
COMMENTS:	

SPECIALTY CARE PROVIDER:	
DATE OF 1ST VISIT:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	
COMMENTS:	



MEDICAL APPOINTMENT SHEET

5 Steps to an effective medical appointment:

- ✓ Write down problems or questions, or both, before you go.
- ✓ Rank your questions from most important to least important.
- ✓ Share the list with your provider.
- ✓ Talk with your health care provider about options for addressing your problems or concerns.
- ✓ Speak with your provider about next steps or follow-up activities.

APPOINTMENT DATE/TIME	HEALTH PROVIDER	HEALTH PROVIDER CONTACT INFORMATION	REASON FOR APPOINTMENT	WHAT WAS DISCUSSED OR DECIDED	FOLLOW-UP REQUIRED/ NEXT APPOINTMENT



PHARMACY PROVIDER INFORMATION SHEET

Tip: If possible use one pharmacy for all of your prescription needs. This will allow your pharmacist to keep track of all medications being used and the potential for interactions between medications.

Use this form to keep track of all of your pharmacy providers.

PHARMACY NAME:	
NAME OF PHARMACIST:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	

PHARMACY NAME:	
NAME OF PHARMACIST:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	

PHARMACY NAME:	
NAME OF PHARMACIST:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	

PHARMACY NAME:	
NAME OF PHARMACIST:	
MAILING ADDRESS:	
TELEPHONE /FAX NUMBER:	
EMAIL ADDRESS:	



INSURANCE INFORMATION SHEET

Use this form to keep track of insurance policy and identification numbers. Record contact information for all health insurance providers for emergency situations.

PRIMARY INSURANCE:	
COMPANY:	
POLICY NUMBER:	
CONTACT PERSON:	
MAILING ADDRESS:	
TELEPHONE NUMBER:	
FAX NUMBER:	
EMAIL ADDRESS:	

MEDICAID/HMO IDENTIFICATION NUMBER:	
POLICY NUMBER:	
CONTACT PERSON:	
MAILING ADDRESS:	
TELEPHONE NUMBER:	
FAX NUMBER:	
EMAIL ADDRESS:	

SOCIAL SECURITY INCOME IDENTIFICATION NUMBER:	
POLICY NUMBER:	
CONTACT PERSON:	
MAILING ADDRESS:	
TELEPHONE NUMBER:	
FAX NUMBER:	
EMAIL ADDRESS:	



MEDICATION LOG SHEET

Use this form to keep track of your medication usage.

MEDICATION (NAME)	DATE		DOSE/ STRENGTH	FREQUENCY PER DAY	PURPOSE OF MEDICATION	SIDE EFFECTS
	START	STOP				

SPECIAL INSTRUCTIONS

Note: List any allergies or changes to medications listed

DESCRIPTION/ BRAND NAME	CONTACT PERSON/ TELEPHONE NUMBER	DATE OBTAINED	SERVICE SCHEDULE	COMMENTS

Medical Equipment: Use this space to record any information related to your medical equipment (description, brand name, size, etc.)



VACCINATION AND IMMUNIZATION TRACKING SHEET

Use this form to record information about your vaccination and immunization history.

NAME:							
DATE OF BIRTH:				BLOOD TYPE:			
VACCINE	DATE	DATE	DATE	DATE	DATE	DATE	TOTAL DOSES
DTP, DtaP, DT							
Td or Tdap							
Hepatitis B							
OPV							
IPV							
HIB (under age 5)							
PCV (under age 5)							
Measles*							
Mumps*							
Rubella*							
Hepatitis A (born after 1/1/2006)							
Varicella*							
MCV/MPSV							
Rotavirus							
HPV							
Nasal Spray Flu Vaccine*							
Td or Tdap (Booster Dose)							

**Check with doctor before live virus vaccines are given.*



TRANSFUSION TRACKING SHEET

Use this sheet to record information about your transfusion history.

NAME:			
DATE OF BIRTH:		BLOOD TYPE:	
TRANSFUSION REQUIREMENTS			
PREMEDICATION NEEDS			

TRANSFUSION DATE	NUMBER OF DAYS/WEEKS SINCE LAST TRANSFUSION	PRE-TRANSFUSION HEMOGLOBIN	COMMENTS/NOTES



LABORATORY TESTING SHEET

Use this sheet to keep track of your laboratory procedures and results.

NAME:					
DATE OF BIRTH:			BLOOD TYPE:		
	Date	Date	Date	Date	Date
COMPLETE BLOOD COUNT (CBC)	RESULTS	RESULTS	RESULTS	RESULTS	RESULTS
White Blood Cell					
Hemoglobin (Hgb)					
Hematocrit					
Platelets					
Reticulocyte* (Retic) Count					
Absolute Neutrophil Count (ANC)					
Other: _____					
Other: _____					

LABORATORY TESTING GLOSSARY	
Complete Blood Count	The complete blood count (CBC) is the most common blood test. The CBC is done to find out the number, shape, and size of the blood cells and the hemoglobin level.
White Blood Cell	White blood cells (WBCs) are cells of the immune system involved in defending the body against infectious diseases.
Hemoglobin	Hemoglobin is the protein molecule in red blood cells that carries oxygen from the lungs to the body's tissues and returns carbon dioxide.
Hematocrit	Hematocrit is a blood test that measures the percentage of the volume of whole blood that is made up of red blood cells.
Reticulocyte (Retic) Count	The retic count is the number of young red blood cells produced by bone marrow being released into the blood.
Absolute Neutrophil Count (ANC)	The absolute neutrophil count is the total number of WBCs in a neutrophil or blood stream.



ADDITIONAL TESTING TRACKING SHEET

Use this sheet to keep track of your laboratory procedures and results.

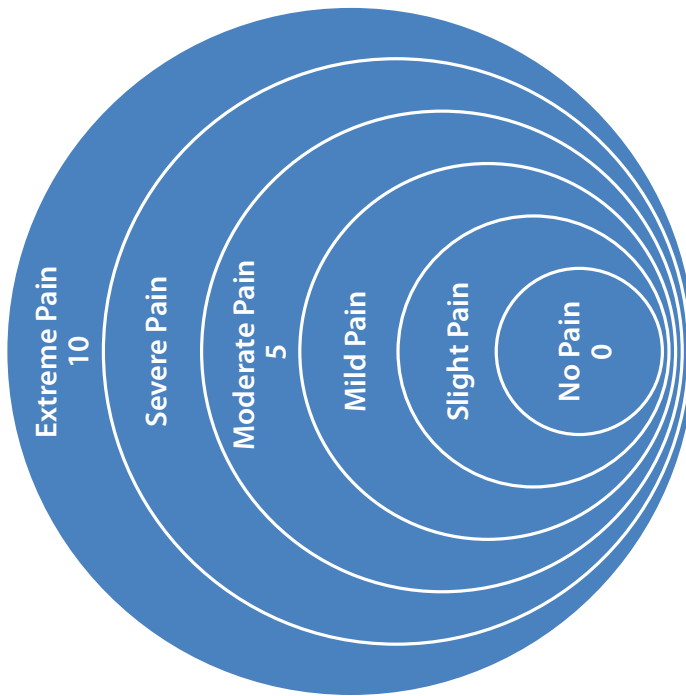
NAME:			
DATE OF BIRTH:		BLOOD TYPE:	

ENDOCRINE LABORATORY TEST				
	DATE	RESULTS	DATE	RESULTS
Fasting Blood Glucose				
Hemoglobin A1C				
T3				
T4				
Thyroid Stimulating Hormone (TSH)				
Free Thyroxin				
Growth Hormone				
Parathyroid Hormone(PTH)				
Follicle Stimulating Hormone (FSH)				
Luteinizing Hormone (LH)				
Estradiol				
Testosterone				
Cortisol				
Glucose Tolerance Test				
Other: _____				
Other: _____				



DAILY PAIN TRACKING SHEET

Use this tracking sheet to record your pain and what you did to relieve it. This will help your health provider to better understand your pain. Complete the form daily and share the information with your health provider at your next visit.

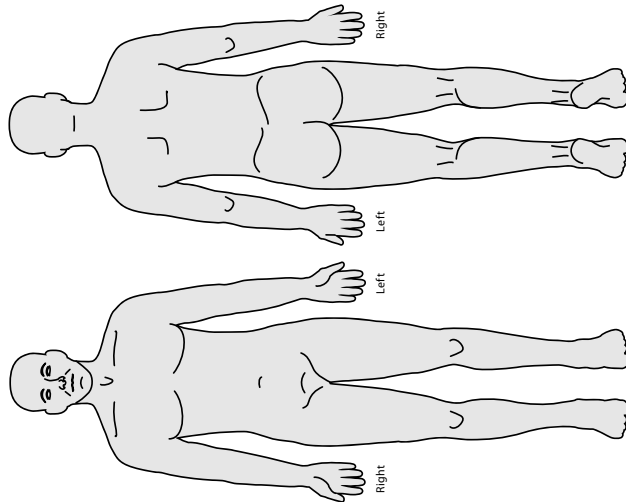


Time (pain episodes occurred)	Rate the pain on a scale of 1-10 (or list the word from the scale that describes your pain level)	What were you doing when pain began?	Did you take prescription medicine (check yes or no)		If yes, what was your pain rating after an hour?	If no, what was your pain rating after an hour?
			Yes	No		
Ex. 6 am	Ex. 5 or Moderate pain	Ex. Walking		No		



DESCRIBE THE PAIN SHEET

Use this form to illustrate where you experienced pain. This form can also be used with your health provider for routine visits or during emergency situations.



1. Using a pen or marker identify the area on the body drawing to illustrate where you experienced pain (use different colors to show more or less pain).

2. Does the pain move or travel across your body? _____

3. Did you cancel, avoid, or limit any of your routine activities today due to pain?

4. Have you experienced different types of pain today?

5. What did you do to relieve your pain today? (Check all that apply)

- Prescription medicine
- Exercise
- Psychological Counseling
- Nonprescription medicine (e.g., Advil)
- Physical Therapy
- Prayer or meditation
- Herbal remedies
- Massage
- Relaxation Technique
- Hot packs
- Rest
- Other _____



STRESS DIARY SHEET

Use this form to monitor and track what causes you stress daily or weekly and what you do to prevent or reduce your personal stress level.

STRESSORS	SHORT-TERM STRESS	LONG-TERM STRESS	STRESS-REDUCING ACTIVITIES



DAILY PHYSICAL ACTIVITY TRACKING SHEET

Use this form each week to keep track of your daily physical activity.

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
Type of activity							
What time and how long?							
Who will participate?							
Did you complete the activity?							
Comments:							



WATER INTAKE TRACKING SHEET

Health providers recommend that people with sickle cell disease drink six to ten 8-ounce glasses of water per day. Use this form each week to keep track of your water intake.

	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Week 1	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:
Week 2	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:
Week 3	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:
Week 4	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:	# of 8-oz glasses:

Week 1 Total: _____

Week 2 Total: _____

Week 3 Total: _____

Week 4 Total: _____

