

How to make the best of your toolkit:

It is important for you to discuss the things that you plan to use from this toolkit with your physician.

Every person with sickle cell disease is unique. Only you know your body and you have to pay attention to it.

Pick and choose what you think will work for you.

Of course, you can add tools that you know work for you.

Using an incentive spirometer (10 breaths 10 time per day) has been proven to decrease the development of acute chest syndrome during a pain crisis.

A community health worker could be helpful in completing your passport to health.

If a patient portal is available to you sign, up for it. This can be very helpful in following your care.

The NHLBI guidelines and ASH trifolds are intended for you to share with your doctor. They are not written in lay terms.

We hope you find this to be helpful!

Personal Information

Name: _____

Address: _____

Date of Birth: _____ Marital Status _____

Phone: _____ Email Address: _____

Type of sickle cell _____ SS _____ SC _____ Sbeta thal zero _____ Sbeta thal plus
Other _____

Usual Hemoglobin level _____

Blood Type _____

Allergies: _____

Emergency Contact: Name _____

Phone # _____

Relationship _____

Insurance: _____

Contract Number: _____ Group Number: _____

Telephone Number: _____

Provider Contact Information

Primary Care Provider

Name: _____

Address: _____

Phone: _____

Specialty: _____

Hematologist

Name: _____

Address: _____

Phone: _____

Specialty: _____

Other Providers

Name: _____

Address: _____

Phone: _____

Specialty: _____

Name: _____

Address: _____

Phone: _____

Specialty: _____

Diagnostic Studies

(X-Rays, MRI, CT Scans, Ultrasounds, Mammograms, TCD)

Date: _____ Ordering Physician: _____

Reason: _____

Results: _____

Comments: _____

Date: _____ Ordering Physician: _____

Reason: _____

Results: _____

Comments: _____

Date: _____ Ordering Physician: _____

Reason: _____

Results: _____

Comments: _____

Blood Transfusion (TX) Record

Date	# of Units	Hemoglobin level pre transfusion	Hemoglobin level post transfusion	Pre-Medication?

History of alloimmunization ____ yes ____ no

Antibodies _____

