



Be ready with questions for your child's doctor - Sickle cell disease

Your child is seeing the doctor for sickle cell disease. This handout will help you list the questions that you want to ask the doctor so you can get the most out of your visit.

? Have your questions ready to ask your child's doctor.

- Check the questions you want to ask the doctor.
- **Learning about sickle cell disease**
 - What is it?
 - What causes it?
 - What are the symptoms?
 - How is it diagnosed?
 - How is it treated?
 - What can I do to help my child?
 - Where can I learn more?
- **Keeping my child's sickle cell disease from getting worse**
 - What can my child and I do to manage the sickle cell disease?
 - What should my child avoid doing?
 - What should my child and I do if the symptoms start?
 - Where and when should I get help if my child gets worse?
- **Taking care of my child**
 - How can I help my child be healthy?
 - What foods should my child eat?
 - What foods should my child avoid?

- How much exercise can my child do?
- How much water or other fluids should my child have every day?
- What are the problems my child could have over time?
- **Questions about my child's medicine**
 - Why does my child need medicine?
 - When should my child get it?
 - How should my child get it (with food or on an empty stomach)?
 - What side effects should my child and I watch out for?
 - What should I do if a dose is missed?
 - What medicines should my child not get at the same time?
- **Tests or shots**
 - Are any shots (vaccines) needed?
 - Are any tests or checkups needed?
 - Blood tests
 - Urine tests
 - Kidney function tests
 - EKG (electrocardiogram), echo test (echocardiogram), or other heart test
 - Eye exams
 - Other: _____
- **Other worries or concerns**
 - Changes in condition since the last doctor's visit
 - Do I need to do anything special to prepare for travel?

- How can I help my child manage the sickle cell disease at daycare or school?
- Has my child been checked for other conditions?
- Write any other questions for the doctor here:



What to do after your child's visit

- Write down these important things.
 - The diagnosis is: _____
 - The treatment (like medicine, health checks, eating plan, exercise) is:

 - The treatment continues until: _____
 - The next doctor's visit is: _____

This information is general in nature and may not apply to you or your condition. Talk to your doctor or nurse about how to best use this information and how to take care of your medical condition. Be sure to ask your doctor or nurse any questions you might have. This information sheet is not intended to provide or replace professional medical advice, diagnosis, or treatment.

Patient or Caregiver:

Signature: _____ Date: _____

Nurse:

Signature: _____ Date: _____