



## Daily care for your child's condition - Sickle cell disease

This handout tells you what you need to do to care for your child's sickle cell disease. Work with the doctor to keep your child healthy.



### Follow your child's self-care plan.

- The self-care plan is a list of what you need to do every day to manage your child's sickle cell disease.
- It tells you the signs that your child's condition is getting worse and when to take action right away.
- Ask your child's doctor or nurse if there are things you do not understand.
- Make and keep all doctor visits.
- Tell the people your child spends time with that your child has sickle cell disease. They should know what to do if your child has a sickle cell crisis.



### Help your child take the medicine as ordered.

- Make sure your child has a supply of pain medicine. Reorder before you run out.
- Know why your child takes each medicine.
- Give the medicine to your child, or help your child take the medicine.
- Know the medicine side effects to watch out for.
- Know what to do if your child misses a dose.
- Keep a list of all the medicine you give your child to show the doctor.
- Get the follow-up tests that your child's doctor orders.



### Do health checks at home.

- Check your child's skin for sores (ulcers) every day.

- Keep a diary of the pain episodes to show the doctor. Write in the diary:
  - Where the pain was
  - Time of day your child had pain
  - How bad the pain was
  - How long the pain lasted
  - What was done about it and if that helped
- To reduce your child's pain episodes:
  - Use warm compresses, a heating pad, or hot baths.
  - Try deep breathing or relaxation exercises.
  - Try to limit movement of the area where the pain is.
  - Keep your child away from the cold. Cold usually makes pain worse.



### **Help your child with a healthy eating plan.**

- Your child may eat their usual foods unless the doctor has ordered a special eating plan.
  - Offer your child plenty of fruits and vegetables.
  - Provide healthy protein, like chicken (no skin), fish, beans, tofu, and nuts.
  - Choose healthy fats, like those found in olive, canola, and peanut oils. They are also in avocados, almonds, walnuts, and fatty fish, like salmon and tuna.
  - Give your child low fat dairy products, like milk and yogurt.
- Prevent painful sickle cell episodes.
  - Give your child extra fluids during physical activity.
  - Help your child avoid caffeine, which is in many soft drinks, energy drinks, coffee, tea, and chocolate.

- Teach your child to not drink alcohol, like beer, wine, hard liquor, and mixed drinks.



### **Help your child take steps for a healthy lifestyle.**

- Help your child to keep active and exercise.
- Learn what can cause a painful episode. Take steps early to prevent one.
- Avoid common causes of an episode.
  - Smoking or drinking alcohol
  - Not getting enough to drink (dehydrated)
  - Doing hard physical activity
  - Fever or stress
- Get a medical ID bracelet or necklace for your child to wear that says your child has sickle cell disease. Be sure your child wears it at all times.
- Teach your child about sickle cell disease as soon as they are able to learn.
- Help your child follow a weight loss plan if they are overweight.
- Teach your child how important it is to:
  - Not smoke
  - Not drink alcohol
  - Not use drugs or misuse medicine
  - Learn healthy ways to manage stress
- Keep up with your child's shots (vaccines).



### **Know the signs that your child's condition is getting worse.**

- Know when to call for emergency help.
  - You think your child is having a heart attack or stroke.

- Your child has very bad breathing problems.
- Know when to call your child's doctor.
  - See the **When to get help - Sickle cell disease, pediatric** handout.

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: \_\_\_\_\_