Pfizer Logo

Managing Sickle Cell Disease as an Adult

Thursday, January 28, 2021

People with sickle cell disease (SCD) are now living longer than they did in previous decades. Doctors have a better understanding of the disease, are able to diagnose it earlier, and can more readily treat and prevent the infections the disease can cause. And thanks to new ways to treat and manage the condition, patients are now more aware of what they can do to live healthier, for longer.

Still, there is currently no widely available or acceptable cure for the inherited blood disorder. Although bone marrow transplant can offer a cure for some patients, the procedure is not without risks. That's why creating a plan for managing the symptoms of the condition can be the key to how an adult can live better with SCD.

Making the Transition from Pediatrician to Physician

Children with sickle cell disease usually have a close relationship with their pediatrician. Their pediatrician may have been caring for them since infancy and therefore knows how the disease impacts them personally—how long painful episodes last and the medications that work best to manage pain.

Many children with sickle cell disease also have parents or other family members who are involved in their care. These family members also serve as advocates for their children's health, from ensuring they make it to doctor's appointments to communicating with the child's healthcare team.

“When these children with sickle cell disease become teenagers and young adults, and stop being under the care of a pediatrician and pediatric hematologist, many can get lost in the medical system,” says Krupa Sivamurthy, MD, Medical Director in the hematology group at Pfizer. “They may feel adrift as they lose the connection they had with their pediatrician and struggle to work with new doctors who may not provide the same level of security they have known previously,” adds Dr. Sivamurthy. Many young adults may also be experiencing other life changes during this time, such as moving from home, which means their family members may be less involved with their healthcare.

So what can young adults and adults with SCD do? How can you ensure you continue to receive the level of care you need and deserve from your healthcare team?

- **Become your own health advocate:** Many pediatricians will help their patients learn to manage their sickle cell disease independently well before they make the transition to general practitioner. Patients can start by learning everything they can about the condition. That way, it’s easier to discuss their health with their new healthcare team. Dr. Sivamurthy also suggests tracking SCD symptoms so you know what triggers painful episodes. You can then work with your hematologist to help identify these triggers. Then be sure to speak up about what you personally need to help you stay healthy and symptom-free.
- **Keep in touch with your doctors:** Find the right primary care physician and hematologist, people who are familiar with sickle cell disease and the health problems it can cause. They should also be doctors you enjoy working with and can easily talk to. To find the right doctors, you can start by asking your pediatrician for referrals and setting up appointments to meet with several doctors before you choose who will make up your medical team.
- **Stay on top of your medical appointments and treatment routine:** Preventative care is especially important for people with sickle cell disease. Make sure you follow your doctor’s recommendations when it comes to getting vaccines, taking medications, and making healthy lifestyle choices. People with sickle cell disease should also see a hematologist at least twice per year or as needed and a primary care physician at least once per year. The exact number of visits you need will vary, though, so be sure to follow your doctor’s recommendation.

[1] [2] [3] [4] [5] [6]

References

- **1.** Ashley-Koch A, Yang Q, Olney RS. Sickle hemoglobin (Hb S) allele and sickle cell disease: a HuGE review. *Am J Epidemiol.* 2000 May 1; 151(9): 839-45. doi: 10.1093/oxfordjournals.aje.a010288
- **2.** National Heart, Lung, and Blood Institute. What is sickle cell anemia? Accessed November 13, 2013.
- **3.** National Heart, Lung, and Blood Institute. The management of sickle cell disease. Accessed November 13, 2013.
- **4.** Peter NG, Forke CM, Ginsburg KR, Schwarz DF. Transition from pediatric to adult care: internists’ perspectives. *Pediatrics.* 2009 Feb; 123(2): 417-23. doi: 10.1542/peds.2008-0740
- **5.** McDonagh JE. Growing up and moving on: Transition from pediatric to adult care. *Pediatr Transplant.* 2005; 9: 364-372. doi: 10.1111/j.1399-3046.2004.00287.x
- **6.** Section on Hematology/Oncology and Committee on Genetics. Health supervision for children with sickle cell disease. *Pediatrics.* 2002 Mar; 109(3): 526-35. doi: 10.1542/peds.111.3.710

Originally published, Thursday, January 28, 2021