

Growing Up with Sickle Cell Disease



“Use the resources that are around you. If you know what they are, use them, and if you do not, try to find them, because the resources are there to help you and to make sure you are on the right track through the transitioning process from pediatric to adult care. Overall, the resources will make your life easier. It will be a better quality of life for you.”

CJ Summers– 21, Computer Graphics Designer

1 of 5 people living with Sickle Cell Disease in North Carolina are young adults (19–29 years) who might be transitioning from pediatric to adult care. This time can be challenging with increasing disease complications and high emergency department use. Using available resources can facilitate the transition process and improve quality of life.

My mom has been very helpful throughout my transition process as well as her knowledge and experience with sickle cell disease. I started talking with my mother about the transition process. We discussed ways to articulate questions to ask the doctors about transition. For example, what medicine I take, and how to access my medical records. To prepare myself, I started scheduling my appointments and calling to refill my medications. I have had tons of help from Piedmont Health Services and Sickle Cell Agency, from their education sessions, transition conferences, and the camp transition sessions that we have done.

When you reach the age where you need to transition from pediatric to adult care, I think before you make the first appointment at the adult center, there should be one last appointment in the pediatric clinic to go over a checklist of everything you know about transition, and what to expect in the adult clinic. Like a handoff between both clinics. When you make that transition, you are considered an adult. Transition is not as scary as it seems, because at first, I was kind of scared of moving on and knowing everything I needed to know.



“There is a point in your life where you know you are growing up, and you just have to step up.”