

HEALTH CARE TRANSITION & SICKLE CELL DISEASE

The process of moving from a child/family-centered model of care to an adult/patient-centered model of care is an important time in the lives of those impacted by chronic illness. Health care transition support for individuals with **Sickle Cell Disease** (SCD), an inherited, life-long condition affecting the red blood cells, is especially dynamic and often requires consideration of multiple factors, including physical, psychosocial, educational/vocational, developmental, financial, and personal responsibility.

WHY IS TRANSITION IMPORTANT?

Outcomes for people living with SCD have been transformed through improvements in health care and treatments over the past 30 years. Life expectancy has increased and individuals with SCD are now living well into adulthood. As survival improves, there is an increasing need for improved coordination between pediatric and adult care. Opportunities to prepare, transfer and integrate emerging adults with SCD into adult care settings is essential in effort to decrease morbidity, enhance quality of life, and reduce mortality.

DIFFERENCES AND CHALLENGES

Parents or caregivers have a main role in helping to manage their child's chronic illness. While they should maintain an active role in the transition process, it is important to encourage emerging adults to get more involved in their own care. The shift to practice more autonomy and develop the skills necessary for successful transition often requires a structured, planned, and guided program. Young adults have reported leaving pediatric care without adequate preparation and often have difficulty navigating the adult health care system that is uniquely different and more fragmented than what they have been used to. The transition to adult care can lead to a decrease in quality of care, increase in acute health care utilization, loss of medical home and breakdown in care coordination. These factors coupled with barriers such as loss of insurance, limited resources, and potential disengagement to follow up also impact health outcomes and well-being.

HOW CAN THE TRANSITION PROCESS BE SUPPORTED?

Transition is a process that occurs over time. It is important to start early to build better outcomes. Preparing for transfer to adult care involves providing parents/caregivers and emerging adults knowledge and skills needed to achieve successful transition.

Education is a key component in the transition process. The increase of mortality and morbidity during this period can be linked to lack of knowledge about SCD and common complications that can lead to serious illness and death. Equipping the emerging adult with educational materials/resources, assessing transition readiness, and helping to find the right provider/comprehensive program are essential in the process. Some hospitals and clinics have transition assistance programs and transition coordinators. These programs offer additional support along with medical care.

TRANSITION RESOURCES

Got Transition®

A federally funded national resource center on health care transition. Identifies 6 core elements of health care transition for 3 different scenarios:

1. Transitioning youth to an adult health care clinician
2. Transitioning to an adult approach to health care without changing clinicians
3. Integrating young adults into adult health care

Sample and customizable tools also available on website.

gottransition.org

Transition readiness checklists

Checklist for Youth: www.gottransition.org/6ce/?leaving-readiness-assessment-youth

Checklist for Parents: www.gottransition.org/6ce/?leaving-readiness-assessment-parent

Centers for Disease Control and Prevention (CDC)

Providing information and tips related to sickle cell disease and transition. Includes stories from people living with SCD.

www.cdc.gov/ncbddd/sicklecell/features/sickle-cell-transition.html

Fact sheet – “9 Tips to Living Well with SCD in College”

www.cdc.gov/ncbddd/sicklecell/documents/scd-factsheet_9steps.pdf

Sickle Cell Transition E-Learning Program – St. Jude Children’s Research Hospital

Offers videos designed as educational modules with interactive pre and post quizzes.

www.stjude.org/treatment/disease/sickle-cell-disease/step-program.html

Sickle Cell Disease Association of America, Inc. (SCDAA)

Offers a peer-to-peer mentoring program to support individuals who are transitioning from pediatric to adult care. Consists of 1-on-1 phone calls and/or text messages that will focus on healthy living with sickle cell disease.

<https://sicklecelldisease.net/peer-to-peer-mentoring/>

South Carolina Sickle Cell Disease Provider State-Wide Directory

Directory of providers, programs and community-based organizations related to sickle cell.

<https://scdhec.gov/sites/default/files/media/document/SC-Sickle-Cell-Disease-Provider-Statewide-Directory.pdf>

IMPACT STATEMENT

The South Carolina Sickle Cell Disease Advocacy Team is a group of stakeholders from multi-disciplinary agencies that include physicians, hematologists, nurses, social workers, care coordinators, government agencies, non-profit organizations, managed care organizations, and families and individuals living with SCD. One area of focus in the state plan is to advocate for each emerging adult with sickle cell disease in South Carolina to have the tools to successfully transition from pediatric to adult care. Our goal is to improve the system of care to ensure individuals living with SCD have a better transition experience.

