

# St. Jude Children's Research Hospital Transition of Care Policy for Patients with Sickle Cell Disease

At St. Jude, we believe a smooth transition to young adulthood includes the move from pediatric to adult health care. Planning and preparing for this change should begin by age 12. At age 18, most young adults in our program will transition to adult health care. The figure below shows the transfer of care and the role of each person during the process.

Our approach to the care of young adults age 18 and older is to protect their privacy, regardless of whether they are being cared for by a pediatric or adult medical team. At 18 years old, young adults are legally in charge of making their own health care decisions and will have the right to share their personal health information with others.

### Model for Managing Patient Care from Infant to Young Adult

#### When the patient is an infant or toddler

The medical team has lead responsibility for managing medical care

The parent directs the medical care

The patient receives the medical care

#### When the patient is school-aged

The medical team partners with the family by providing guidance and support
The parent manages the medical care by guiding and advocating
The patient takes part in medical care, decision-making, and self-advocacy

#### When the patient is a teenager

The medical team serves as a consultant for managing patient care

The parent supervises or coaches the teen with shared decision-making and advocacy

The patient has a primary role in medical care through shared decision-making and self-advocacy

## When the patient is a young adult

The medical team serves as a resource for managing patient care

The parent serves as a consultant for managing patient care

The young adult directs the medical care, is the lead decision-maker, advocate and supervisor