

## Sam's Story

Sam is a 4-month-old baby with Down syndrome born to Jessica and John. He is their second child; he has a 3-year-old sister, Emma. The extended family lives close by and is a support to the family. The maternal grandmother has provided extra childcare for Emma during these early months, as Sam has required follow-up with a pediatric cardiologist in another city. A heart defect was identified on a prenatal ultrasound, and diagnostic testing has indicated that Sam will need cardiac surgery, most likely within the next year. At this time, his condition is stable, and he is at home being cared for by his mother, who has taken a leave of absence from her job while his father has returned to work after taking some time off following Sam's birth.

Sam's parents find that they need to provide greater support to Sam's head and body than they did his sister. They understand that this is due to decreased muscle tone, which is characteristic of Down syndrome. Sam seems interested in moving but has limited success. Jessica thinks he might be reaching for her, but his arms seem floppy. He moves his legs while being bathed and seems to enjoy the water. Jessica has not observed him moving from his side to his back. Sam is not yet able to hold his head steady when an adult is holding him while moving. Toys placed in his hand are held for a short while, but he doesn't attempt to bring the toy or his hands to his mouth.

Sam is developing a more consistent routine. When awake, he is attentive to his parents' faces, and when his head is supported, he will follow their moving bodies with his eye and at times turn to look for their faces when they move out of sight. He will follow a bright toy held over his head, and he turns his head to loud sounds. The family has heard him make the sounds "ooh" and "ahh," but he has not imitated sounds presented to him. Sam is not showing signs of sleep apnea.

Feeding was a challenge at first. Sam had a lot of difficulty latching. His parents worked with a speech therapist at the hospital, who had them try a number of different nipples as well as breastfeeding. He would try but just didn't seem to be able to get enough milk out before he was exhausted from trying. After what seemed like an endless number of nipples and positions for feeding, Sam finally began getting enough milk through a very soft nipple with a slightly enlarged hole. Sam's parents have to watch very closely that Sam is able to manage the flow without aspirating the milk. He has been feeding well since they got home, and the family is wondering if they could try some solids. They had introduced solids to Emma when she was about 4 months old. Sam's parents are a little concerned that Sam's tongue is often out and wonder what people are talking about when they say, "tongue thrust." Does Sam have this, and what does it mean?

Sam passed newborn hearing screening in his right ear but failed in his left. The screening was repeated two more times with the same results while they were still at the hospital. Sam saw a pediatric audiologist when he was 4 weeks old. Tympanograms (testing of his middle ear) were completed, suggesting that Sam had fluid in his middle ear on the left side, which could explain his not passing the hearing screening. The family returned when Sam was 2½ weeks old. The fluid was still there, and Sam was referred to an otolaryngologist (ENT) for medical follow-up. That appointment is yet to come. Sam's parents feel like he can hear them. He brightens when they say his name and talk to him. He has been vocalizing, mostly vowels. He can get quite loud; as John says, "Good lungs on that boy!"



Typical and Atypical Child Development  
Module 1: Birth through 3 Years of Age  
Case Study

This is the first child with Down syndrome in John and Jessica's extended family. Sam's grandmother has been exploring on the internet. Her friends have been talking with her about some interventions that they have heard of, e.g., use of Namenda (a memory medication) to improve cognition. John and Jessica are not sure and wonder if medications would be valuable or possibly harmful.

*Summary*

*Jessica and John are concerned about the upcoming cardiac surgery but are hopeful that Sam will have more endurance after the surgery and will be able to progress in his achievement of motor skills. They are pleased that he is drinking adequately and is gaining weight. They understand that he will progress at a slower rate than his age mates in skill development. Jessica is concerned that she hasn't been able to spend enough time with Emma since Sam was born.*

*Sam has Down syndrome. Cardiac surgery is recommended in the future. Low muscle tone affects movement and likely feeding. He is likely to experience global developmental delays and will need therapy and special education programming. The family seems resilient, and things have become easier for them now that Sam is at home. Support for the family may be important given the medical and educational complexities of raising a child with Down syndrome.*

*Follow-Up Questions*

- 1. Due to Sam's history of feeding difficulties, although feeding has improved, how long do his feedings usually take, especially since his parents have to watch for aspiration?*
- 2. Is he receiving any therapy services, either through Birth to 3 or in a clinic setting?*

