

## Noah's Story: Are You Listening?

### Learning Objectives

- Recognize the importance of clear communication with patients and their families during a care experience.
- Discuss how everyone in a health care organization — from physicians to housekeepers — can contribute to better patient care.
- Examine the importance of following organizational protocol when caring for patients.

**Description:** Follow the care experience of four-year-old Noah and his mom, Tanya. A surgery, a series of miscommunications, and an early discharge from the hospital contribute to an adverse event that changes the family's life forever. The patient story includes several discussion questions and concludes with an emotional video that gives readers Tanya's perspective on the devastating experience.

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Noah Lord is born — by Cesarean section — on January 25, 1995. He is a healthy baby, meeting all his milestones except for expressive speech. This means that Noah is not making the normal babbling sounds expected from an infant, but this a minor concern.

At 2-years-old, Noah develops an extensive expressive speech delay. He speaks, but only his parents are able to easily understand him. A hearing test and other evaluations show that Noah has mild hearing loss due to chronic ear infections and fluid buildup in his ears. Noah's otolaryngologist (ear, nose, and throat (ENT) specialist) decides that Noah needs a set of ear tubes to allow drainage of fluid. Getting rid of the fluid, the ENT specialist hopes, will increase Noah's hearing and improve his speech.

Noah undergoes surgery in 1997 and, slowly, his speech improves. As Noah recovers from surgery, the ENT specialist teaches Tanya how to evaluate her son for obstructive sleep apnea. At home, Tanya picks random times at night to listen to Noah sleep, and records every time he snores or takes a breathing pause. After watching Noah for several nights, she is certain he does not have sleep apnea and reports this to his ENT specialist.

In 1999, Noah and his family move from Boston to Cherry Hill, New Jersey. Now that Noah is 4-years-old, his speech has improved to the point where he is ready to graduate from his special needs pre-school and speech therapist. However, his ear infections begin again and, in the spring of 1999,

the family consults another ENT specialist in Philadelphia. At the initial appointment, the nurse asks Tanya about Noah's sleep patterns and, specifically, about his snoring. Lately, Noah has been snoring on and off, so Tanya answers, "Yes, he snores." Tanya also offers the information that she had observed Noah's sleeping patterns two years before in Boston and explains he did not have sleep apnea. The ENT specialist determines that Noah needs another set of ear tubes, and that he needs his adenoids and tonsils removed, too. Confused but determined to help Noah and not stunt his progress, Tanya signs the consent forms for the surgery.

**Pretend you are Noah's mother. What else could you have done at this point to advocate for your son?**

About a week later, Tanya calls the ENT specialist. She is concerned about the upcoming procedure, and schedules another appointment to discuss her questions. A week before the scheduled surgery, Noah and Tanya once again meet the ENT specialist. Tanya explains that, as a child, she had symptoms similar to Noah's and only had an adenoidectomy (adenoid removal). She adds that Noah had been snoring at the time of their last appointment, but it was only because he had been congested at the time. Now, she says, he no longer snores. She reminds the ENT specialist about her sleep apnea assessment in Boston and asks to only have tubes inserted and the adenoids removed. He tells her that if they wait, she will be returning in six months to get the tonsils out. The ENT specialist adds that "it would be cruel to subject him to two separate procedures," so he might as well have them both out. Tanya consents to the surgery.

**Tanya has made an extra trip to express her concerns, brought new information and family history, and made it clear that she did not want Noah to have an unnecessary surgery. Was the ENT specialist listening to her? Why or why not?**

On June 11, 1999, Noah undergoes the outpatient procedure. The care team reports that the procedure is uneventful. Noah is in the recovery room, but refuses to drink. He consistently vomits and won't speak. Even though the surgeon tells his parents that he will not be released from the recovery room until he is drinking, Noah is discharged a few hours after surgery.

Noah continues to vomit at home, and refuses all drink, food, or medicine by mouth. He develops a slight fever, begins a constant cough as if he is clearing his throat, and stops urinating. Tanya calls the on-call ENT resident five times that first day to report Noah's worsening symptoms. At first, the resident tells her that Noah's vomiting is because of the anesthesia, then because he is in pain because he isn't taking oral meds. He suggests using Tylenol suppositories. He asks Tanya if Noah is vomiting blood. She looks at her son's vomit and answers, "No."

**Tanya didn't understand that the coffee ground-colored vomit was likely blood that had been swallowed and was now coming back up. How could she and the resident have avoided this simple, yet important, miscommunication?**

The following day, Sunday, Tanya's concern continues and she calls the covering resident three more times. She asks if someone can take a look at Noah. She brings him to the emergency department (ED) around 11 AM. The evaluation shows that Noah is severely dehydrated, and he is admitted to the extended ED, an observation area within the department. The care plan is to monitor Noah for up to 23 hours while nurses provide him with IV fluids, medication to stop the vomiting, and morphine for the pain. Noah continues to refuse anything by mouth and is very lethargic. Becoming increasingly concerned, Tanya questions the nurses. But the nurses covering that area of the ED are from a float pool and are not familiar enough with Noah's condition to answer her questions. An attending physician puts his head into the room and asks Tanya how things are going. She answers, "Okay," and he steps out without evaluating Noah or the surgical site. With her worry growing, Tanya gently grabs hold of the next staff person she sees and leads her to her son's bedside. "Please help him," she says. "He is not doing well at all. This is not how my son would normally be. He is really sick and I am so worried! Please tell me what is wrong." The woman smiles, shakes her head, and says, "Ma'am, I am here to collect the garbage." She replaces the bag and leaves.

**What opportunities to help Noah did the staff – including housekeeping – miss in this situation?**

On Monday morning, the ENT specialist calls the ED and tells Tanya that Noah will be sent home with a PICC line because of dehydration. An hour or so later, a nurse comes in, explains that a visiting nurse will come to Tanya's house at 6 PM to hook up an IV to the PICC line and asks Tanya to sign a paper, which she assumes is a consent form. After several hours, Noah's symptoms continue (and get worse), and Tanya goes to the nurses' station to request to speak to a physician. They tell her that Noah has been discharged (that was the form she had signed) and there is nothing they can do. Tanya calls her husband, Glen, and he comes to pick them up. Later that day, the ED attending comes by on rounds. He is not aware that Noah has been discharged; his assumption is that Noah's parents had insisted on leaving.

**No physicians examined Noah before discharge, which violated hospital protocol. How could this have happened and what could have prevented it?**

At home, Noah continues to cough, and refuses food or drink. Three hours after arriving home, while resting on the couch, Noah begins to hemorrhage from his surgical site. He aspirates the blood and stops breathing within minutes. Tanya, a trained life guard, calls 911 and begins CPR. She clears Noah's airway three different times, but by the time EMS arrives, Noah is dead.

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### **Discussion Questions**

1. Watch the video at <https://youtu.be/LUDJhmcDEzA>.
  - How does hearing from the patient affect your feelings about this story?
2. How can we prevent Noah's experience from happening with another patient?
3. How can we prevent Tanya's experience from happening to another patient's family member?