Tips for treating children with autism
To minimize patients’ acting out, rely on careful planning and consistency

by Tammy Worth

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Talk to Casey Drake, MD, about the challenges of treating autistic children in the hospital, and she recalls the family who moved a wingback chair into the hospital room. The chair was the patient’s favorite, and letting him sit in it during exams and blood draws made for a much smoother hospitalization.

While harnessing the familiar is critical for autistic patients, Dr. Drake says that it doesn’t have to be as labor-intensive as moving furniture. It can be as simple as mixing liquid medications with a drink in a favorite cup or turning over the care of a patient to a colleague of the opposite gender.

“Some don’t like women or men or blonds, or people who talk too loud or too soft,” explains Dr. Drake, who is president of Drake Hospitalists, a private pediatric hospitalist group in the Dallas area. “Some don’t like to be touched on the top of their hand.”

To reduce anxiety for both patients and staff, Dr. Drake tries to learn what may trigger patients’ erratic or defensive behavior. “We try as much as possible to accommodate patients,” she says, “and modify our behavior to match their needs.”

While that’s the same creed physicians bring to all patients, the reality is that treating patients with autism typically requires more time and education. And with autism rates on the rise, pediatric hospitalists need to think about strategies for dealing with a population that appears to be growing rapidly.

Control the environment
According to Fighting Autism, a national nonprofit organization, the number of autistic individuals between the ages of 3 and 22 skyrocketed from 93,650 in 2000 to 259,705 in 2006. Experts say these numbers likely represent an increased awareness about the disease, which is leading to diagnosis at an early age.

As the father of an 8-year-old son with autism, Erich Maul, DO, is something of an expert on treating children with the condition. The pediatric hospitalist, who works at Kentucky Children’s Hospital in Lexington, is called to consult on most of the autistic patients who are admitted.

“They frequently have disruptive behaviors, such as screaming or physically acting out,” Dr. Maul says. “Doctors need to realize that socially unacceptable behavior can be normal for children with autism.”

So how should pediatric hospitalists prepare to work with these patients? In addition to gathering as much information about patients as possible (see “What do you need to know?” on page 36), physicians should also try to make the factors that go into a hospitalization as consistent as possible.

Start by limiting the number of physicians and nurses interacting with autistic children. Dr. Maul says this can be a problem at academic centers, where attendings often enter the room as part of “a huge galloping hoard” of residents and medical students. When doctors insist on rounding with their entire group of residents, he explains, “some of these kids are going to act out.”

Mary Didie, MD, a pediatric attending at Blythedale Children’s Hospital in Valhalla, N.Y., says she not
only tries to limit the number of physicians and staff who treat an autistic child. She also works to use the same nurses and assistants whenever possible, and suggests that a family member be in the room 24 hours a day.

And because many autistic patients have ritualized eating fetishes, Dr. Didie tries to maintain a sense of consistency at mealtimes. “When you can,” she says, “offer these patients a diet they will eat, feed them at the same time and, if need be, even present the tray in the same way each time.”

Guard against sensory overload
Experts urge physicians to understand patients’ sensory sensitivities. Many are susceptible to sensory overload, while others may be much more tactile and visual than non-autistic children. Hospitalists can use those characteristics to their advantage.

“Some kids can’t get a haircut, let alone a shot,” says Aubyn Stahmer, PhD, a psychologist and research scientist at the Autism Intervention Center, which is part of Rady Children’s Hospital in San Diego. “If you can find and change things that are going to be noisy or bright ahead of time, it’s helpful.”

The center’s Web site offers a number of strategies to help maintain a low-key environment for patients with autism. Tips include dimming lights, keeping noise levels low, touching children infrequently and getting their attention to let them know what will be happening next.

And because children with autism are very visually oriented, Dr. Stahmer says, her hospital posts photos online of different steps in frequently used procedures. That way, parents and patients can get comfortable with the hospital environment before ever stepping foot in the building.

“For some kids, it’s like magic,” Dr. Stahmer says, adding that parents could take their own pictures of different areas of the hospital or the physicians who will be treating their children.

Harness visuals and touch
Rady Children’s Hospital also relies on visuals in-house. The EEG department, for instance, keeps a photo album in its waiting room with pictures of the procedure.

And because children with autism may be averse to tactile stimulation, the EEG department sometimes recommends that parents have children practice wearing a hat similar to the EEG cap prior to the procedure. During an EEG, children can also play with a box of old machinery parts that remind them of the machines in the room.

To make exams easier for autistic children, many physicians encourage allowing autistic children to manipulate their tools of the trade. Dr. Didie recommends setting up instruments like an IV in advance and talking to children about them.

At Blythedale Children’s, child-life specialists—counselors who provide support for families and help children deal with hospitalization through play, preparation and education—use dolls to demonstrate procedures before they are performed. If patients are old enough, specialists will often let children perform the procedure on their own dolls.

“If something might upset a patient, such as wearing a hospital gown or having an arm band put on, let them feel and touch and get used to it one thing at a time,” Dr. Drake recommends. “You might have to slow things down and let them get used to each new thing.”

Time and planning
Physicians who are used to working with autistic patients acknowledge that this population will almost always require more time and energy than other patients. They say that as a result, a little planning can go a long way. Dr. Drake recommends steering clear of distractions by turning off pagers and phones and making sure that there are enough staff scheduled to work with the patient.

“Schedule everything in advance,” she says. “Make sure the hospital—from admitting to the patient’s ultimate destination—knows the patient coming in has autism spectrum disorder.”

Michelle Marks, DO, the head of pediatric hospital medicine at Cleveland Clinic Children’s Hospital, says that because each patient’s triggers are different, hospitalists should spend time interacting with children to get a feel for what their baseline is and how sick they are. Some children who are aggressive when they are well become very quiet when ill. Others who normally are “well-behaved” may bite or kick when they don’t feel well.

“Some people expect that they will be able to move quickly through these visits,” Dr. Marks says. “You have to spend a lot of time talking with patients before you can even touch them, and you are very often doing a moving exam because the kids are always moving. But you can’t rush in.”

**Enlist parents**

Parents are invariably a hospitalist’s best resource in determining how to approach and proceed. Many families with autistic children, says Dr. Maul, rely on reward systems or other behavioral strategies, so parents might already have tactics that work when giving medications or calming children down. When his own son was age 4 and suffering from chronic strep throat, Dr. Maul recalls, a liberal dose of Oreo cookies was the best way to entice the child into taking liquid antibiotics.

But while parents can be your allies, Dr. Maul notes that there is a “very vocal minority” of parents who are suspicious of physicians and medicine. “They try alternative therapies and worry that mainstream medical folks won’t understand them or accept them,” he says. “The hardest thing to do is break down the walls of communication, especially if a nurse comes out and says, ‘Oh my God, she is a fruit loop, she is doing X, Y, Z.’”

Dr. Maul says that it’s important to be honest while at the same time keeping an open mind. One area of potential conflict that often comes up is the issue of immunization. Some families continue to believe, Dr. Maul points out, that vaccines played a role in their child’s autism.

“Many families refuse to immunize or want alternative schedules, despite our evidence of safety,” he says. He says that he makes sure patients are making an informed consent, at the same time that “I give them the respect of hearing their viewpoint. Sometimes we find compromise, or we agree to disagree.” It helps to remember, he says, that he needs to be the child’s advocate, even if his point of view and the parents’ are diametrically opposed.

“The folks who tend to venture more into alternative therapies are outspoken and well-educated,” Dr. Maul explains. “It is typically the squeaky wheel who gets heard, and these folks tend to squeak very, very loudly.”

Many of these parents have had a great deal of experience with physicians and tend to be more hospital-savvy than the average parent.

“They know these children well and want to participate in their medical care,” says Dr. Marks from the Cleveland Clinic. “They are the only ones who know what is normal for their child. If you’re smart, you are going to utilize them to your advantage.”
Weigh the risks
What should you do if a quiet room or parental guidance won’t soothe a child? Fortunately, medical advances have given hospitalists some alternatives to sedation.

Alternatives include improved sedatives, liquid medications, topical anesthetics and pain management programs. Dr. Marks also points to the fact that there are more ancillary services for inpatients than in years past, including pediatric psychologists and child-life specialists. Such advances have led to “a recognition that we can use other strategies than sedation,” Dr. Marks says. “Previously, we didn’t use other modalities as much as we do now.”

Another approach is to scale back on patient care. If it’s too difficult or unsafe to perform a procedure, for instance, it’s time to weigh the benefit of the test against the risk to the child.

How do you know when to move forward and when to let something slide? “Sometimes you have to just try to get what you can,” says Dr. Maul. If a test or procedure is necessary to make a diagnosis, he adds, “you need to press on as you would with any other child.” But he urges physicians to think again if the test in question is “a fancy confirmatory lab test when you’ve already made the diagnosis.”

At the same time, however, Dr. Drake in Dallas notes that physicians have to fight the urge to forgo necessary tests and procedures. Because colleagues have passed on performing difficult exams, she has seen missed ear infections, abscessed teeth and severe constipation. All were problems that could have been easily treated.

“Sometimes you have to look in that ear and that solves the whole problem,” Dr. Drake says. “It is a difficult balance between providing comprehensive care and making patients more anxious.”

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What do you need to know?

THE AUTISM INTERVENTION CENTER at Rady Children’s Hospital in San Diego has devised a questionnaire for parents to fill out before or during admission. The questionnaire asks for information on the following 10 areas:

1. What is the best way to comfort your child?
2. Does your child enjoy deep pressure or squeezes?
3. Does your child avoid eye contact or being in close proximity to others?
4. Does your child communicate through speech, pictures, sign language or gestures? How should we communicate with your child?
5. What are your child’s favorite food or beverages?
6. What types of toys or activities does your child prefer?
7. Does your child have difficulty with transitions? If so, what tends to help?
8. Does your child respond to visual cues? Would a video or picture example of a procedure help?
9. What was your child’s last doctor or hospital visit like? What parts were most difficult?
10. How we can make this visit easier for your child?
Where to look for help

ACCORDING TO PHYSICIANS who work extensively with autistic patients, local community support groups can be a valuable resource. Support-group members can speak at staff meetings, be called in if a family needs assistance or suggest resources for families after a patient leaves the hospital. Online resources also include:

- The Autism Intervention Center at Rady Children’s Hospital San Diego has an online section of physician resources that includes a resource guide, screening tools and links to other Web sites (www.rchsd.org/autism).
- The Help Autism Now Society provides information to help children prepare for treatment, including online story books on getting blood drawn and visiting a doctor’s office (www.helpautismnow.com).

Tips for sedating patients with autism

Inpatient medical advances have now made it possible to rely less on sedation for patients with autism than in years passed. But when sedation is called for, the same factors that help with any inpatient treatment—learning in advance about patients' triggers and sensory issues—are even more important. That's according to Laura Badwan, MD, hospitalist site leader for the pediatric intensive care unit at Children's Memorial Hospital in Chicago who also works on the sedation team.

"Talk to patients' families to assess patients' autistic characteristics and find out what has worked best in the past," Dr. Badwan says. You need to know, for instance, if a patient has an oral aversion, which should steer you away from using an oral sedative. Dr. Badwan also offered the following tips:

- In addition to discussing the care plan with the family, have caregivers talk through the procedure to the level of the patient's understanding. Sometimes, Dr. Badwan explains, autistic patients have some component of mental retardation. "It is helpful," she says, "to ask the parent what the child's developmental age level is."
- Encourage families to stick with their normal routine or schedule on the day of sedation. "Perhaps try to schedule the sedation time around a normal nap time," she says.
- Have parents bring favorite toys or drinking cups to the procedure. These will help distract children while they are in the sedation area.
- Try to have a "quiet room" available for the patient upon arrival pre-sedation and also post-sedation. "Some children are more affected by certain types of light and noise," says Dr. Badwan. "Set a room aside that can be sealed off from other environmental stimuli while the patient is being evaluated for sedation and while recovering."
• For patients who don't have an oral aversion, consider an oral Versed dose before IV placement. "Sometimes these children are combative when being held for IV placement," Dr. Badwan points out. "A dose of Versed may calm the patient enough to make it easier to successfully place an IV on the first try."

• In addition, Versed has amnestic properties so the patient will not remember the event. Dr. Badwan also recommends using the new J-tip injector with aerosolized lidocaine for IV placement to lessen any pain associated with the initial IV stick.

• Keep in mind that some autistic children may be more combative during sedation and require more medication.

"Try to elicit this history from the family if the patient has been sedated in the past," says Dr. Badwan. If previous sedations have been difficult due to combative behavior or if the patient awakens from sedation, consider referring to an anesthesiologist for sedation with other methods in the future.