

Special Needs

Treating Patients with Fetal Alcohol Spectrum Disorders

BY RICK ASA



Kathy Mitchell's daughter, Karli Schrider, is 37 years old. For both women, it's been a long road paved by alcohol.

Karli was diagnosed with fetal alcohol syndrome (FAS) at age 16, although she had chronic ear infections (*otitis media*) almost from the day she was born that could have tipped off health care professionals that something was amiss. Kathy began the march from clinic to clinic in search of answers early in her daughter's life, only to be told that Karli had colic and allergies but no evidence of disabilities and that she would "grow out" of her conditions. Karli's intellectual and growth development was delayed, Kathy was told, because of the ear infections.

At age 9, Karli was "diagnosed" with cerebral palsy, one of the many disorders and conditions whose symptoms overlap with those of FAS. She was always sick, her mother says, and couldn't shake it off.

Kathy, a recovering alcoholic, got sober after another daughter died in infancy. Sober-living allowed Kathy to regain her life and even attend college. As her world expanded, she became aware of FAS and a special clinic at Georgetown University, where Karli finally was diagnosed with FAS.

"She would not have been diagnosed if I hadn't figured it out, and that's so true in so many cases of FAS," says Kathy, now the vice president and spokesperson for the National Organization on Fetal Alcohol Syndrome (NOFAS).

Kathy spends at least \$3,000 a year on her daughter's dental care, which has included frequent cleanings, many restorations and crowns, and a lot of time. She attests to "some traumatic sessions" with dentists over the years. Karli had to be sedated beforehand just to go to a dentist's office early on, and her mother believes that Karli was traumatized at one office in particular. Karli desperately needs the care, however, because she has lost many of her teeth to oral disease, partly as the result of poor hygiene at home.

FASD affects an estimated 40,000 infants each year in the United States—more than spina bifida, Down syndrome, and muscular dystrophy combined.

But something as physically simple as brushing one's teeth every day—and understanding the importance of it—can be a daunting challenge for people with FAS, and Karli is no exception. Even now, Kathy sometimes tries to intervene with some well-intentioned help, but Karli "doesn't like her mother putting her toothbrush in her mouth."

Kathy says that professional oral care—i.e., "the dentist problem"—is an oft-discussed issue in FAS circles, yet she believes that dentists are a critical part of the health care team for people with FAS. When parents find a dentist who is prepared for and sensitized to children and adults with FAS and its manifestations, she says, it's like finding gold. That dentist has a patient for life.

Although appointments may take longer for patients with FAS and can involve gadgets or anticipatory materials, such as visual aids, that

help patients cope in the dental chair, there are psychological, emotional, and financial rewards, says Stephanie Mihalas, PhD, a child and adolescent psychologist in Los Angeles, Calif., and an adjunct professor at Pepperdine University.

"There are many FAS support groups, and when these groups find out that a dentist is seeing this population and has behavioral strategies in place, you can rest assured that the dentist will receive a plethora of referrals," Dr. Mihalas says. "And for

the dentist, even if the upfront cost might seem high, the cost-to-benefit ratio is slanted much more toward the benefits."

Jason Grinter, DDS, director of special patient care at Illinois Masonic Medical Center in Chicago, adds, "Families and caregivers of special needs patients appreciate the special skill that goes into treatment and are more likely to refer their own non-afflicted family and friends to the practice."

But dentists often don't give themselves enough credit, Kathy Mitchell believes, and see the treatment of FAS patients as being beyond their ability. "Dentists can make a difference by just helping FAS patients to feel okay about themselves or getting the families to move in the right direction when it comes to care," she says. "If I were a dentist and I suspected a patient had FAS and the family wasn't aware, I would do everything I could to get the family to seek help, because the research is very clear that the earlier the diagnosis, the better the outcome."

One part of a wider spectrum

All types of fetal exposure to alcohol are increasingly referred to as *fetal alcohol spectrum disorders*, or FASD, which is not a diagnostic term used by clinicians but an umbrella designation that encompasses the huge range of clinical effects that can occur in various combinations.

In general, those effects fall into physical, intellectual, and behavioral categories that stem from damage that occurs in the womb. The most severe form of FASD is FAS. Another term, fetal alcohol effect (FAE), is sometimes used to differentiate patients who do not present with a range of typical facial characteristics tied to alcohol exposure and have less severe behavioral and neurological issues. FAS is considered the “tip of the FASD iceberg,” according to the NOFAS. Other FASD may be more difficult to accurately identify. (See “Finding Common Ground,” below.)

Alcohol causes neuronal damage and cell loss in the fetal brain, on which it acts as a toxin or teratogen. Other human teratogens of note include ionizing radiation, lead, polychlorinated biphenyls (PCBs), prescription medicine used to treat epileptic seizures, substances of abuse (e.g., cocaine), and infectious agents. “Although the effects of exposure to many of these compounds are well described, the mechanisms of action are not,” wrote the authors of a paper in *Northwest Dentistry* (January/February 2004). “Teratogens differ in their periods of susceptibility, the duration of exposure required to cause adverse fetal outcome and the manifestation of the insult.”

According to these authors (from the University of Minnesota), current research is attempting to identify the specific mechanisms of fetal damage caused by alcohol exposure, but many factors have made the search complicated. The authors say that the ways

in which alcohol impacts each fetus depends on “many variables such as the timing, frequency, and amount of maternal drinking during pregnancy.” Often, that level of exposure is not known.

Defects caused by prenatal exposure to alcohol have been identified in virtually every part of the body, according to the Substance Abuse & Mental Health Services Administration (SAMHSA). Those areas include the brain, face, eyes, ears, heart, kidneys, and bones. “No single mechanism can account for all the problems that alcohol causes,” the SAMHSA notes. “Rather, alcohol sets in motion many processes at different sites in the developing fetus.” Because patients with FASD can be at high risk for several types of heart defects, many cases will require a consult for precautions against bacterial endocarditis prior to any dental treatment, says Steven Perlman, DDS, MScD, founder and clinical advisor for Special Olympics

FINDING COMMON GROUND

By Kari Fletcher

Use the following tips to ease the treatment experience for the dentist, the patient, and the patient’s family:

For the Dentist

- Listen to what the parent says about the child.
 - Ask for ideas from the parent to help the child.
- Be kind to the child—use humor and be happy.
 - Make the exam area feel safe.
 - Prevent distractions, such as knocks on the door, etc.
 - Let the child look at the equipment.
 - Provide a play/pretend area.
 - Learn about the child’s interests and document them.
- Use full-spectrum lighting.
 - Consider having a lava lamp in the operatory.

For the Parent

- Make appointments during the less stimulating part of the day and at a time when your child is at his or her best.
- Consider the location and the environment—fluorescent lights, type of music played, etc.
- Use noise-blocking headphones and calming music.
- Bring a pair of sunglasses for your child to help avoid light glare.
- Write a note to the dentist, listing your child’s areas of sensitivity as well as the best way for the dentist or his or her staff to handle any behavioral issues.
- Search for a dentist who works with children with special needs.

Appointment Tips for the Parent and Child

- Visit the dentist one or two times before the appointment to allow your child to meet the dentist and his or her staff.
- Tour the clinic or office during one of your preliminary visits to allow your child to become familiar with the surroundings.
- Bring an item that will comfort your child.
- Ask the dentist to model procedures on you while your child watches. Let the child practice sitting in the dental chair.
- Encourage the dentist to practice procedures on your child without actually doing them.
- Ask your child about the overall visit experience.
- At home, read simple books that explain going to the dentist, doctor, hospital, etc.
- After the visit, sit with your child in the reception area and make four pictures before you leave. Ask your child to draw everything he or she smells on one page and everything he or she sees, hears, and tastes on the other pages. This will become your child’s “Going to the Dentist” book. Laugh and enjoy the time together. Fill in the drawing with words that you want your child to remember from the experience.
- After the visit, do something fun with your child. Do it because your child completed the visit; forget about how the child behaved during the visit. This fun activity can be as simple as going to the store for a new toothbrush.

Kari Fletcher is the regional resource coordinator, southern Minnesota, Minnesota Organization on Fetal Alcohol.

Special Smiles® (SOSS) and Boston University faculty member.

Dr. Perlman acknowledges “considerable disagreement” over the exact mechanism by which the fetus is affected, but adds that emerging evidence indicates that the critical period seems to be gastrulation and mesoderm formation, “which occurs just a few weeks after conception when many women are unaware that they are pregnant and/or are not cognizant of consequences to the embryo.”

To date, no “safe or prudent” level of alcohol consumption during pregnancy exists, meaning that even one or two drinks can lead to FASD, says Dr. Perlman. Therefore, says Kathy Mitchell, expectant mothers should be counseled that there are no safe levels of alcohol consumption during pregnancy.

Prevalence of FASD

Another slippery slope, FASD prevalence, has been the subject of many educated estimates. One widely referenced estimate for FAS places it at 1.9 per 1,000 live births (nearly 0.2 percent), although some epidemiologists have placed it as high as one in 650. It is believed to be the third most common cause of intellectual disability worldwide and the leading cause of disability in the Western world. Evidence to date indicates that FAS occurs in 30–45 percent of infants born to chronic, heavy

child’s neurological differences. If we can’t, we work hard to educate and provide support for both the professional and our child.

We keep a tight routine in our home. Random appointments are a transition from our normally structured day. This means we tell our children that the appointment is a normal, routine thing to do and that people go to the dentist to be healthy and we must do this a few times a year. Sometimes, we explain, we have to do it more

often when there is a problem so we can get healthy.

We provide gentle cues to our children with hand gestures, pictures, and simple verbal commands. We are happy to teach professionals about the cueing that our children understand.

Some of our children are overly sensitive to pain and others do not feel it. My friend’s son pulled out his healthy solid baby teeth to get money from the Tooth Fairy. He had heard in school that

other children got money under their pillow. He told his mom that “pulling his teeth didn’t hurt one bit!”

Remember, ultimately we’re on the same side—we both want the child to be healthy. The child wants to feel good and be able to have a happy life.

Kari Fletcher is the regional resource coordinator, southern Minnesota, Minnesota Organization on Fetal Alcohol.

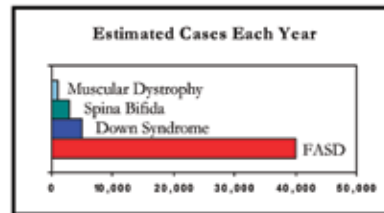


National Organization on Fetal Alcohol Syndrome

Educating the public, professionals and policymakers about alcohol use during pregnancy

FASD: WHAT EVERYONE SHOULD KNOW

Alcohol use during pregnancy is the leading known preventable cause of mental retardation and birth defects in the United States.



FASD affects an estimated 40,000 infants each year – more than Spina Bifida, Down Syndrome and Muscular Dystrophy combined.



Fetal Alcohol Spectrum Disorders (FASD)

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects can include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. Fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (PFAS), alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD) are terms used to describe the range of conditions associated with prenatal alcohol exposure. An FAS diagnosis indicates the most serious set of birth defects, including growth deficiency (physical), central nervous system dysfunction (mental or brain damage) and a characteristic set of facial dysmorphism or malformations.

Who is at Risk?

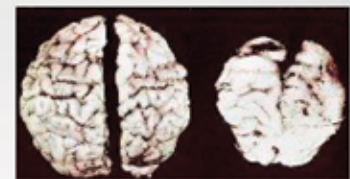
Any woman of childbearing age is at risk of having a child with an FASD if she drinks alcohol during her pregnancy. Alcohol can harm an embryo or fetus at any time, even before a woman knows she is pregnant. Many women drink early in pregnancy but stop drinking when they learn they are pregnant. Others cannot stop drinking without help. Women who have given birth to children with an FASD and continue to drink are at very high risk of having additional children with an FASD.

What Are the Effects of FASD?

Depending on the timing and frequency of maternal alcohol consumption outcomes associated with prenatal alcohol exposure may include:

- Specific facial dysmorphism
- Growth deficits
- Brain damage including mental retardation
- Heart, lung, and kidney defects
- Hyperactivity and behavior problems
- Attention and memory problems
- Poor coordination or motor skill delays
- Difficulty with judgment and reasoning
- Learning disabilities

“Of all the substances of abuse (including cocaine, heroin and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.” *Institute of Medicine, 1996.*



Normal Brain

FAS Affected Brain

Harvard, Am. J. Med. Genet. 2002

FASD also takes an enormous financial toll on affected families and society as a whole. Less than one-third of individuals affected prenatally by alcohol have the full FAS, yet FAS alone costs the United States \$5.4 billion annually in direct and indirect costs. This is only a small portion of the total societal costs associated with FASD.

How Can FASD Be Prevented?

While there is no cure for FASD, it is 100 percent preventable when pregnant women abstain from alcohol. NOFAS prevents FASD by raising public awareness, training practitioners to screen women for alcohol disorders and teaching youth to make healthy choices, among many other strategies.

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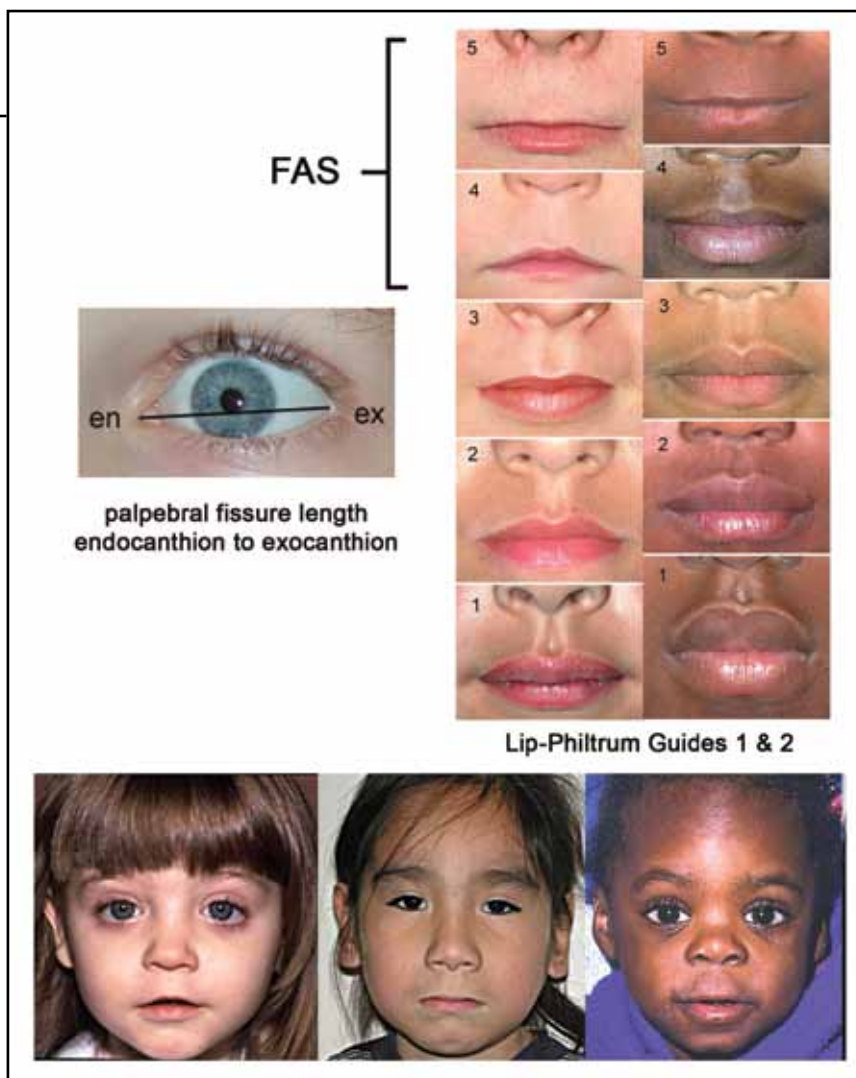
This fact sheet by the National Organization on Fetal Alcohol Syndrome (www.nofas.org) offers information at a glance for medical and dental personnel and their patients.

UNDERSTANDING FASD CHILDREN

By Kari Fletcher

Parents with children who have neurological differences have to pre-think and educate everyone who comes into contact with their child. We know that we cannot change behaviors that are caused by organic brain damage. When things are not working, we have learned to change the environment or circumstances to help our child manage. Fighting with a child with FASD only makes him or her dig in deeper and resist.

We do our best to find professionals who understand our



The FAS facial phenotype is characterized by the following three minor facial anomalies: (1) palpebral fissure length 2 or more standard deviations below the mean; (2) smooth philtrum (Rank 4 or 5 on the Lip-Philtrum Guide); and (3) a thin upper lip (Rank 4 or 5 on the Lip-Philtrum Guide). Examples of the Rank 4 FAS facial phenotype for Caucasian, Native-American, and African-American children are shown.

drinkers. According to the NOFAS, FASD affects an estimated 40,000 infants each year in the United States—more than spina bifida, Down syndrome, and muscular dystrophy combined.

An epidemiological review published in 2009 (*Developmental Disabilities Research Reviews*) focused on data produced from in-school studies on FASD in the United States, South Africa, and Italy, which contrasts with three more widely used prevalence-related methods. The authors concluded from the data that FAS and other FASD are more prevalent in school populations, and thus in the general population, than previously estimated.

The authors believe that the prevalence of FAS in typical mixed-

racial and mixed-socioeconomic populations in the United States is at least 2–7 per 1,000. When all levels of FASD are taken into account, the authors estimated that the prevalence in younger school populations may be as high as 2–5 percent in the United States and some western European countries. In the United States, this could amount to one child in every class, says Ajeet Charate, FASD program director for Trinity Services, Inc., which administers the NOFAS Illinois.

"If this is true, then FASD presents a larger public health problem than most researchers have estimated in the past," writes principal investigator Philip A. May, PhD, an epidemiologist

and faculty member at the University of New Mexico, in the September 2009 edition of *Developmental Disabilities Research Review*. "The problems of FASD require immediate attention and emphasis from the public health, obstetric, pediatric, and educational communities."

Kathy Mitchell believes that this new research, which was conducted over a five-year period, is more representative of the actual prevalence of FAS and FASD because in the past, the federal government relied more on birth data registers and information coming out of diagnostic clinics that didn't capture the "true numbers." She also notes, however, that the study didn't involve children who could be considered FAE because the schoolchildren included in the sample had to meet at least some of the physical criteria for measurable growth inhibition.

Clinical findings and characteristics

Many patients with FASD have certain orofacial characteristics that can help lead to an accurate diagnosis, an important factor because other manifestations of FASD, particularly behavioral ones, overlap with those for many other distinct conditions such as attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD), autism, and depression. "Diagnosis of FAS is very complicated and takes a team of skilled professionals," says Dr. Grinter. "Dentists are in a unique position in the community in that they see patients on a more frequent basis than a typical physician. Dentists should learn to look for obvious facial signs of FAS."

According to the NOFAS and other experts, those signs include small palpebral fissures; "railroad track" ears; a thin upper lip; a smooth (indistinct) philtrum; a flat nasal bridge; epicanthal folds; an upturned nose; and distance between the upper and lower eyelids (see images, at left). If a dentist notices these signs and the patient is not formally diagnosed, the dentist should consult with the family physician before any treatment is provided,

"Dentists are in a unique position in the community in that they see patients on a more frequent basis than a typical physician. Dentists should learn to look for obvious facial signs of FAS."

as well as pursuing "the need to report the findings along with the physician to their state child welfare services, as dentists are typically mandated reporters in most states," Dr. Grinter says.

Other classic symptoms include documented growth deficits, documented central nervous system (CNS) abnormalities, developmental delay, intellectual impairment, microcephaly, and microphthalmia. Many patients with FASD, such as those with FAE, do not exhibit the orofacial signs, which explains why FASD is sometimes referred to as the "invisible disorder." Many also have higher IQs and therefore appear to function at higher levels, which hides their disability, says Mr. Charate.

"The majority of children with FASD are diagnosed well after birth," he says. "Most are six to eight years old when symptoms manifest—and nobody can figure out what's going on. Most are children of foster or adoptive parents trying to find out what's wrong and, when they start digging, they find out that their children may have come from a birth mother in a country where alcohol use is high. Since the disorder includes children who don't have the physical characteristics, it's challenging. The child's day-to-day performance is uneven. There are days in which they behave normally in terms of their age, but most days they may be performing at half their age level. A 14-year-old might be functioning at a normal 8-year-old's capacity."

Kate Johnson*, a suburban Chicago parent of an adoptive child with FASD, is familiar with most of what Mr. Charate says. She adopted her daughter, Courtney*, from Russia in 2002. She had no classic signs of FASD, and the adoption agency, Mrs. Johnson says, turned out to be "less than forthcoming" about her child's medical history. During the first year, there were mostly medical problems. Once Mrs. Johnson and her husband had a handle on those issues, "all the behavioral stuff" rose to the surface, she says. "It turned out that Courtney had no attention span, couldn't socialize with other children at day care, and was disproportionately aggressive toward them. She was even biting some of them. Before long, the day care's administrators got fed up and asked us to leave."

Frustrated and confused as Courtney's behavioral problems worsened, the Johnsons took her to a specialty clinic in Washington, D.C., similar to what Kathy Mitchell did with her daughter many years before. The physician who

* Pseudonym

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diagnosed Courtney told the Johnsons that, based solely on a video of their daughter, “a first-year medical student could have diagnosed her [with FASD].”

In the past year, Courtney has been hospitalized four times for various illnesses. The Johnsons also learned that Courtney had a stroke at birth.

Despite the obvious errors, conscious or otherwise, that were made in Courtney’s adoption process and her continued behavioral challenges, the Johnsons have found a dental home for their daughter. And, like most parents of children with FASD, Mrs. Johnson says, “She’s a really neat kid, very loving, and has great qualities” that balance her parents’ frustrations.

“It’s trial and error with dentists,” she says. “It comes down to finding somebody your child can trust. The

first time we saw him, he pulled up a chair and talked to her for a while; and you could see that she felt very welcomed. After two or three visits, I could sit in the waiting room during her appointment; and she felt great that she could do it by herself.”

Finding a dentist who was able to successfully interact with and treat her child was no small accomplishment for Mrs. Johnson. “I’m on a [FASD] list serve, and once a week the question will pop up: ‘Does anybody out there have a good dentist?’”

Academy of General Dentistry (AGD) member Jon L. Hardinger, DDS, MAGD, of Mason City, Iowa, has achieved the AGD’s Mastership award through continuing education. Still, even as an educated dentist, it’s noteworthy that he admits to a lack of

knowledge of FASD and the lifelong problems it carries.

“I was unaware of my own ignorance of the problem—I did not know about FAS until recently,” he says. “I only learned about FAS through Internet resources. The photos I saw there were a help to me in seeing the orofacial signs, which help me to screen a patient. My treatment experience with FASD began by being more aware of the symptoms and asking the mother of a foster child if her son had FAS.”

Dr. Hardinger learned quickly that the patient was different from other teenagers. Although the boy attended regular classes in school, his mother acknowledged that he didn’t always do well. She said that he often would act as if “he had ants in his pants” and sometimes exhibited bad judgment,

TREATING THE FASD PATIENT

Because the extent of developmental delay, physical abnormalities, and intellectual ability varies from patient to patient, each one requires individualized and specific care. Some patients may require sedation, general anesthesia, and a referral if they need a lot of work or are very young, chronologically or developmentally, and unable to cooperate with or withstand treatment.

Oral challenges in patients with FASD can include soft enamel; rampant caries; mouth breathing caused by facial deformities, which leads to dry mouth; poor tongue thrusting; temporomandibular joint (TMJ) disorders; cleft lip/palate; malocclusion; and maxillary overjet. Tooth eruption in children with FASD often comes very late. Again, the extent and level of orofacial abnormalities run a wide range and are highly individualized. Systemic abnormalities, such as heart defects, also require that dentists be fully aware of the patient’s medical history, contraindications for certain medications, and all abnormalities that come into play during treatment.

“Most often, however, FASD patients just need a little extra time and patience,” says Jason Grinter, DDS, director of special patient care at Illinois Masonic Medical Center in Chicago. “Any office that is used to working with pediatric patients or patients with disabilities should have no problem treating a FASD patient. The biggest predictor I find in whether a patient can be treated in a typical office setting is whether the dentist feels comfortable and has experience in understanding the challenges an FASD patient may pose, such as behavioral barriers that limit cooperation.” These barriers can include lower than normal levels of memory, language, attention, reaction time, visuospatial abilities, executive functioning (managing one’s self and one’s resources to achieve a goal), fine and gross motor skills, and social and adaptive functioning, according to a FAS review paper in *Orthodontial Craniofacial Research* (2006).

A tendency toward sensory abnormality, known as “sensory integration disorder,” also can make patients with FASD hypo- or hyper-responsive to light, sound, and other types of stimuli. For instance, these patients can be

resistant to having their teeth brushed, meaning that the parent, guardian, and dental staff “need to be extremely diligent and extremely dedicated to assisting the patient with his or her oral hygiene,” Dr. Grinter says.

He adds that the biggest predictors of oral problems in patients with FASD are lifestyle choices often passed on from generation to generation, such as poor oral hygiene and a diet high in sugar. He also notes that patients with FASD are often in foster care and therefore are insured through a state Medicaid program. This can be a huge barrier to needed care, as many dentists are unable to accept Medicaid patients because of low reimbursement rates.

General dentists, however, likely will also see patients with FASD who have been adopted or are still with their birth mothers, as in the case of Karli Schrider. In these instances, being thoughtful and prepared can make treating a patient with FAS mutually rewarding and less difficult than most dentists would believe.

Stephanie Mihalas, PhD, a child and adolescent psychologist in Los Angeles, Calif., and an adjunct professor at Pepperdine University who has consulted on FASD in various settings, suggests that dentists acquaint themselves with the variety of behavioral symptoms that can arise. Patients with FASD, for instance, may seem distant and inattentive at first. That may be true, but it’s not willful, she says. They may make funny sounds or may be still playing with a doll at age 10, one that they insist on holding. They can even be very “clingy” with the dentist, Dr. Mihalas says, which the dentist might find strange and off-putting if he or she doesn’t understand that patients with FASD do that simply as a result of emotional immaturity and a need to be comforted. For those reason and others, she says, it’s important for dentists treating patients with FASD not to overreact, as this can create a counterproductive behavioral cascade in the patient.

Since patients with FASD also may exhibit short-term memory deficit(s), the dentist may become frustrated that everything he or she just said about what’s going to be done that day is quickly forgotten. One way to help the

As part of the health care team, dentists should know what to look for when treating FASD patients and they should help other health care professionals to diagnose patients early on.

another common trait of FASD. The boy's mother also noted that he had a tendency to forget repeated advice, such as reminders to brush his teeth every day. "He has had problems with his orthodontic treatment and, despite the abnormalities that led to the braces, he still sucks his thumb at age 16," she says.

Due to the behavioral issues tied to FASD, "there are things he just doesn't understand," she says. "The day-to-day challenges are behavioral, things

like getting up in the morning, brushing his teeth, eating, and so forth. They're just things that he doesn't consider to be important. What's important to him are things most of us take for granted, like family. People are very important to him."

Dr. Hardinger says that his eyes have been opened to the possibilities for children with FASD, particularly with early intervention. Learning about FASD and its effects is extremely important for general

dentists, Dr. Hardinger says. As part of the health care team, dentists should know what to look for when treating FASD patients and they should help other health care professionals to diagnose patients early on. Equally as important is for dentists to know how to interact with patients with FASD, which isn't always easy. But as the parents and loved ones of people with FASD say, once you make that connection, you'll have a patient for life. ♦

Rick Asa regularly contributes to *AGD Impact*. Mr. Asa lives in Westmont, Ill., and has been a full-time freelancer for 13 years. Prior to freelancing, he was national media manager for the American Dental Association, a science editor, and a newspaper reporter. To comment on this article, send an e-mail to impact@agd.org.

patient follow the treatment from beginning to end is the use of picture cues. These cues have no words and are usually laminated and outfitted with Velcro®, which allows them to be attached close to the patient and an assistant who can change them easily and avoid interrupting the treatment flow. Cues can keep patients with FASD calm when they become overwhelmed but can't process or remember verbal explanations, Dr. Mihalas says.

Patients with FASD also tend to have a poor sense of time and may constantly ask the office staff, "How much longer?" or start fidgeting. Dr. Mihalas says that various instruments can help patients with FASD keep track of time in a manner that they can understand. In other words, a standard clock won't work. Instead, use a special clock or a timer that can be set for five minutes, the time it will take for one segment of the treatment. In addition, Dr. Mihalas suggests using a chart that documents each successful interval, maybe with a smiley face sticker, so that patients know they are earning something. This can help them to maintain their motivation through the usual distractions. In the end, earning enough stickers for a stuffed, plush tooth could be all the motivation the patient needs to get through the treatment.

Showing versus telling also works. For instance, show the patient the instruments that will be used and let him or her touch them. Other solutions for behavioral challenges include buying some funky sunglasses (e.g., pink, tiger-striped, or cartoon character-themed) and letting the patient choose which ones he or she wants to wear. Sometimes a relaxation bag placed over the eyes can help, but a patient with FASD might tire of it quickly. You may have to switch back and forth between sunglasses and the relaxation bag during a single visit.

Liz Kulp, 24, a patient with FASD who has written two award-winning books to help families deal with the condition, says that she is "still dealing with dental issues and change is a really hard thing. Not having a body [that works like everyone else's] is full of surprises. On my twenty-fourth

birthday I [was] in the dental chair getting a wisdom tooth taken out that had what the dentist called 'stringy roots.' I hoped not to get a dry socket—but I did—and then not to get infected—which I did—and then not to get side effects from the antibiotic—which I did ... then because of the side effects, I lost potassium; and because of that, it took another month to get healthy again. It's frustrating to deal with issues than can spin me and everyone else out of control. Thank God I have a good dentist who has taken the time to get to know me and care about my needs. Sometimes I think I must drive him crazy."

Ms. Kulp implores dentists to consider the following based on her own experience: In addition to sights and sounds, smells, touch, and space can be issues for her. So, she asks, let her choose the flavor of the toothpaste she will use, give her more anesthetic to help with the "touch sensitivity," and remember that dental work involves "being in my space, so I may need a time out to regroup."

"Don't just tell me what to do for aftercare, give me a list of three important points in simple language: one, things to do; two, what to expect that's normal; and three, a number to call for help. Teaching me to do something needs to be a hands-on experience. Show me and don't talk. Talk and don't show, and then let me try it," Ms. Kulp says.

Ms. Kulp's mother, Jodee, adds, "Braiding a dental relationship into a young child's life can provide consistency through adulthood. Setting a quality dental routine of cleanings and dental care provides structure in a person's life. Changes in relationships and routines can upset an FASD patient's day and create havoc, both pre-appointment and post-appointment."

If you want to get involved with FASD or other types of special needs patients, Dr. Grinter suggests that you "start small and see if you like it. Treat more straightforward patients first, build your confidence and skills, and soon you'll develop a reputation in the community as a caring and compassionate dentist."