

Dx IQ #3:

Why Your Child is More Likely to Be Misdiagnosed Than You Are

By Helene M. Epstein

Most kids are healthy most of the time. Beyond the usual tumbles and falls, the boo-boos that can be healed with a kiss and a Band-Aid®, beyond the normal childhood illnesses that sweep through classrooms as if by the power of suggestion, kids do tend to be healthy.

However, the mindset that young children are rarely seriously ill is one of the main reasons that they are more likely to be misdiagnosed than adults are. That's on top of all of the ways that approximately 10 percent of American adults are misdiagnosed every year (See [Dx IQ #1: The most important medical issue ever](#) for more). When doctors and nurses expect to see a healthy child with a common short-lived illness, they may miss the uncommon ones (See [When parents' concerns are dismissed](#) below).

The top reasons young children are susceptible to a diagnosis that's wrong or delayed include:

1. Attitude: Since most children are healthy, and most illnesses resolve on their own, doctors may tend to reassure parents rather than accept concerns are real
2. Biology: Young children's bodies and systems are radically different than adults, so they present and respond in unexpected ways
3. Unequipped: Most children's emergency room visits are to community or adult hospitals that often don't have needed kid-sized equipment or pediatric experts. Urgent care centers have similar issues.
4. Communication: Young children don't understand or know what is wrong so they're dependent on parents or caregivers to recognize and then interpret their symptoms

When parents' concerns are dismissed

Sometimes diagnostic error happens slowly and there is time to catch it and course correct, but every so often it occurs lightning fast. Isabel was a healthy three year old in London who woke up one morning with normal chicken pox and was fighting for her life a few days later.

Her mother, Charlotte Maude, took Isabel to their family physician that Tuesday morning because she "had an innate sense that something was not quite right." She had a fever of 104 degrees (40 degrees Celsius) with diarrhea and frequent vomiting. However, they were reassured by the family physician this was normal chicken pox and Isabel would heal without any interventions.

However, that evening Isabel's fever has risen and she had a rash all over her lower torso and groin, so they took her to the local emergency room in London. The family asked the junior doctor (the rough equivalent of an intern in the U.S.) what else this could be. The staff was so focused on getting the fever down they never considered other causes of the fever. The family was sent home at midnight.

All parents will experience the need to balance between trusting and respecting the doctor, and trusting and respecting our knowledge of our own kid. When the experts tell you your child is fine, is it dismissal or reassurance? Jason Maude, Isabel's father, calls this a "dangerous thing because our instinct as parents was 'this isn't quite right' but the message you want to hear as parents is 'your kid's fine.'"

By 8 am Thursday morning, Isabel's condition had worsened and they returned to the emergency room. "It turns out this decision saved her life," Charlotte Maude notes.

Her blood pressure was so low, the nurse first assumed the machine was broken. Ten minutes later, Isabel's eyes rolled back in her head and she collapsed in her parents' arms. The staff finally realized the situation was serious and they battled to stabilize her. "Suddenly pandemonium broke out," Jason adds, "You think what the hell happened? ...She was here with the chicken pox and now you're telling me she might not make it?"

Isabel was transferred to an intensive care unit at another hospital in central London. "That's when they told us she's got [necrotizing fasciitis](#) (NF) and [toxic shock syndrome](#) (TSS)," says Maude. NF is a bacterial infection, commonly known as flesh-eating disease, which kills the body's soft tissue. Toxic shock syndrome is often associated with NF and refers to the release of poisonous substances from an overgrowth of staph infection. "You've got to get it within the first 24 hours," Maude says.

It was touch and go for weeks. Isabel had more than twenty surgeries over an 18-year period. Today Isabel is a healthy 23-year-old college graduate working in London. The Maude's co-founded a company and a state-of-the-art tool with the goal to help healthcare providers worldwide avoid missing serious illnesses like the junior doctor missed in Isabel. They also provide a [free symptom checker](#) for patients.

Looking back, Maude says there was a simple missed opportunity in their first emergency visit when they asked the junior doctor what else it could be. If the doctor had stopped and considered what he was observing and what the parents were sharing, he might have realized that high fever and frequent vomiting are signs of a serious infection. A simple round of penicillin would have stalled the deadly flesh-eating bacteria.

Children are not just little adults.

"It's all about developing bodies," says Dr. Prashant Mahajan, Vice-Chair, Department of Emergency Medicine and Professor of Emergency Medicine and Pediatrics at the University of Michigan. As bodies mature, he says "their anatomy, immune system, neurological system, and psychology development" change, too. Many children's medical conditions look, sound, and feel differently so they need to be diagnosed and treated differently than adults, too.

Serious bacterial infections, like Isabel's necrotizing fasciitis and toxic shock, or more common ones like [sepsis and septic shock](#), are dangerous for everyone, but infants and children have a [higher risk](#) of developing sepsis. The [signs of sepsis in younger children](#) vary from those for adults (For the signs of sepsis in children, [click here](#).) Sepsis is a leading cause of death for children, three times greater than pediatric cancers. It is both swift and difficult to diagnose.

Pediatric cancers are also more difficult to diagnose quickly and grow far more quickly than adult cancers do. According to Dr. Robert Hayashi, Professor of Pediatric Hematology/Oncology at St. Louis' Washington University School of Medicine, some tumors even double in size each day they are undetected. In fact, for 80% of children with cancer, it has already spread to other parts of their body by the time it is diagnosed. Dr. Hayashi says, "Families are often upset because their children present with

such extensive disease and they feel that there was an oversight in the evaluation.” However, he adds, “that is actually rarely the case.”

Of course, that is cold comfort to the family of a child whose cancer is missed. Dr. Andrew White, who is a rheumatologist and immunologist at St. Louis Children’s Hospital, tells the story of a 5-year-old boy who came to the hospital with pain in his wrist and shoulders. Over the past six weeks, “Timmy” (not his name) had already seen his pediatrician twice, plus several visits each with two other specialists.

As is true for most hospital patients, Dr. White’s patients usually see a resident or an intern before they get to him. “As the resident is presenting the symptoms and the lab results, I’m already thinking about what it could be: it could be rheumatic fever, it could be fracture, it could be cancer, it could be juvenile rheumatoid arthritis...categorizing it as I hear the story. As I look at the labs, the list shifts in my head.”

The resident suggests they just “give him some Advil, see him back here in a few weeks, and see what happens.’ So I turn to him as we’re walking down the hall. ‘Tell me why this isn’t cancer.’” The resident is startled.

Dr. White was correct. Timmy had a type of leukemia that has a high rate of cure, “pre-b-cell ALL”. White says he knew it as soon as he approached Timmy in the exam room. Timmy had a “gigantic wrist.” As White approached him and lay a hand softly on the child’s arm, he pulled away abruptly. “Subtle little signs,” says White. “Juvenile rheumatoid arthritis (JRA) is not like that. They don’t even know their wrist hurts that much. If I approach and it’s so tender, that’s one of the signs we pay attention to. So I felt his lymph nodes, look at the labs, and I know it’s cancer.” White added that in retrospect, the very first set of x-rays indicated cancer but it was so early, it was easy to miss.

While there’s nothing lucky about getting cancer, children’s cancers are [far more curable](#) than adults’ cancers; close to 90 percent of kids survive a pediatric cancer. That’s partly because most adult cancers are carcinomas, while [children’s cancers](#) are usually leukemias, lymphomas, sarcomas, and gliomas. The same mechanism, rapid cell growth, which makes pediatric cancers grow so quickly is the key to their much higher rate of cure. Dr. Hayashi explains it further, “Rapidly growing tumors are invariably sensitive to chemotherapy. And because chemotherapy capitalizes on the cell’s ability to divide, the more it divides, the more it’s susceptible to the chemo. Oftentimes we literally see tumors disappear within a week because of their sensitivity.”

One Size Doesn’t Fit All

One of the biggest issues for children experiencing an emergency is that “85 percent of children end up in a community based or adult emergency room where the diagnostic team is not experienced caring for a child,” says Dr. Mahajan. He notes that “the equipment isn’t appropriately sized and the mind set isn’t either.”

Stroke rarely happens in children but it is one of the top 10 causes of death. Because it’s uncommon, and because [stroke in young children](#) can sometimes present differently than it does in adults, diagnosis is often delayed. Delay treating stroke is harmful for any age, but for young, developing bodies, it may be catastrophic. To Mahajan’s point, general emergency physicians may not consider stroke for a young child and they may not have the appropriate equipment or access to pediatric specialists.

Laney Fitzsimons died at the age of four because stroke wasn't considered in time. [Note: Laney's story comes from a [published medical study](#).]

In May 2016, three-and-a-half-year-old Laney was taking a bath "when she suddenly started speaking with a slight slur. It was subtle, and we attributed it to her being tired." Two weeks later she started to slur her words again and her face drooped. The emergency physicians diagnosed her with seizure disorder. An MRI was ordered but never happened. Because the hospital wasn't a pediatric hospital, they didn't have an emergency pediatric anesthesiologist available, necessary to help a child in distress keep still long enough to complete an MRI. Dr. Lisa Sun, a pediatric cerebrovascular neurologist from Johns Hopkins School of Medicine, notes it isn't the norm for general emergency centers to have such specialized personnel available.

A few days later it happened again, but the symptoms were worse, affecting her ability to walk and speak. The Fitzsimons went to a different hospital, still not a pediatric hospital. Again she was diagnosed with a seizure disorder. She saw a pediatric neurologist a week later, who confirmed a diagnosis of complex partial seizure disorder and told the parents they could wait three months for the MRI to "give Laney a break."

Almost a month after Laney's initial symptoms, she woke up unable to stand, speak, eat, or drink." The EMTs brought Laney back to the second hospital, which transferred her to a larger hospital "where doctors concluded that she was tired from her seizures." On June 6, 2016, an MRI was finally done and showed Laney had "suffered multiple acute strokes and had severe brain damage."

In December 2016, Laney suffered another stroke and, after other attempts to intervene failed, she went into hospice care. She passed away at the end of March 2017.

Her parents and Dr. Sun jointly published a [study in *Pediatrics*](#), the official journal of the AAP because, "...the death of a bright, beautiful 4-year-old girl inspires a family to dedicate her legacy to this noblest of causes: spreading her story so that someone else's child may live."

Dr. Sun writes, "In any adult, [Laney's initial symptoms] would have been immediately recognized as a warning sign of impending stroke. But because Laney was three years old, they were misdiagnosed as complex partial seizures." Seizure is more common than stroke in young children. Sun cites a small study saying "arterial ischemic stroke was only considered as a possible diagnosis in a quarter of cases of childhood stroke despite" relevant symptoms in 86 percent of those cases.

Getting the full history

Dr. Richard McClead, Associate Chief Medical Officer of Nationwide Children's Hospital in Columbus, Ohio, suggests the most common reason patients of any age are misdiagnosed is that the doctor or nurse don't get all of the important facts. There are many reasons for that (See [Dx IQ #1: The most important medical issue ever](#) for more).

Children have more hurdles to telling the full story than most adults do. The biggest issue is communication. Short of a cut or a bruise, very young children can't explain what they're feeling. Babies don't speak and toddlers don't have the right words. They need their parents and caregivers to recognize what's happening and explain it to a doctor or a nurse.

“We are dependent on a caregiver to interpret the symptoms,” says Dr. Mahajan. “Sometimes the parent has to offer information if a question isn’t asked. The key to a diagnosis may lie in something that was not asked or told.”

Mahajan tells the story of a six-month-old brought into the emergency room by his dad. He looked well, the fever wasn’t particularly high, so they sent them both home with instructions. The next day, the mom returned with the same baby, same fever, and told the pediatric attending an important fact the dad had left out. Mom was HIV positive and had been before the pregnancy began. That one piece of information completely changed the emergency physician’s approach to the baby’s symptoms. Was the baby immune-compromised? It turned out he was born HIV positive and the fever needed to be addressed with greater urgency. Mahajan says they ordered “a comprehensive evaluation including blood tests, urine tests and a lumbar puncture...to rule out meningitis.” He was given intravenous (IV) antibiotics for 48 hours and then sent home, well.

Parents also need to put a child’s symptoms in context for the pediatrician. For example, talk about how energetic your child usually is and why her recent loss of energy is worrying. Or tell the doctor that your son has lost his appetite and is much quieter than usual.

Dr. McClead agrees in the importance of listening to parents. He advises, “Parents need to be able to speak up and be the advocate for their child.” To do that properly, parents have to be organized. You should always have a list of the child’s current medicines, latest vaccinations, and previous health issues easily available. It’s so much harder to gather or recall that data in the midst of a crisis.

McClead recommends that parents speak up even though it can be awkward to do. Calmly sharing the facts at your fingertips makes it easier.

What you can do for your kids now

Don’t get overwhelmed by the risks of misdiagnosis; your kids are too important. There are a few key things you can do now to help get an accurate and timely diagnosis, before any trouble arises. These tips also work if your child is in the middle of a diagnostic journey today.

1. Dr. McClead urges parents to sign up for the doctor’s or hospitals’ patient portal and check the records thoroughly. “Is the information correct? Are the medications and medical history correct? Read it, correct it, and tell the doctor” or the staff.
2. Important test results can slip through the cracks and that may lead to misdiagnosis and lack of treatment. Keep track of any tests that are done on your child. That includes blood tests, urine tests, x-rays, and any other type of scan. If your child has a test, simply ask when the results are expected and note it in your calendar. If you don’t get called or emailed with results, call and ask about them. Remember, “No News is No News.” Don’t accept being told, “We will call you if there’s a problem.”
3. Trust your gut. You’re the people who know and care about your child the most. All of the experts encourage parents to speak up if they feel their child’s symptoms aren’t getting enough attention or if there’s any confusion between what the family is saying and the medical professional is hearing.

4. If your child isn't showing signs of improvement, get a second opinion. Ask friends and family members in town for a recommendation of a pediatrician in a different practice, or ask your current pediatrician for a specialist to give a second opinion.
5. Be prepared before you bring your child to the doctor or an emergency room. While your child is healthy, check if there's a pediatric urgent care or emergency room close to where you live. If you have a planned appointment, there is a valuable tool you can start using today. The [SIDM Patient Toolkit](#) is a handy step-by-step workbook with sections to fill out before, during and after your doctor's appointment.
6. If you're using the internet to look for more information, be sure to use reliable and trusted sources. The American Academy of Pediatrics' (AAP) [Healthy Children section](#) is a great place to begin. You can also try Jason and Charlotte Maude's [free symptom checker](#) for patients.

If your child's primary healthcare provider doesn't offer a patient portal or easy access to your child's records, or if they bristle at being asked questions or getting corrected information, it might be time to find a new practice. And please share this article; you may help someone else's child.

The Society to Improve Diagnosis in Medicine (SIDM) catalyzes and leads change to improve diagnosis and eliminate harm from diagnostic error. We work in partnership with patients, their families, the healthcare community, and every interested stakeholder. SIDM is the only organization focused solely on the problem of diagnostic error and improving the accuracy and timeliness of diagnosis. In 2015, SIDM established the Coalition to Improve Diagnosis, to increase awareness and actions that improve diagnosis. Members of the Coalition represent hundreds of thousands of healthcare providers and patients—and the leading health organizations and government agencies involved in patient care. Together, we work to find solutions that enhance diagnostic safety and quality, reduce harm, and ultimately, ensure better health outcomes for patients. Visit our website at www.improvediagnosis.org, and follow us on [Twitter](#) or [Facebook](#).

Helene M. Epstein writes about patient safety and family health. Her goal is to help readers apply important new information to their own lives. [Subscribe](#) to her posts, visit her [website](#) or follow her on [Twitter](#) or [Facebook](#).

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