



Jonathan Kantor for Newsweek

Jasmyn Rose Wilkinson, an 18-month-old patient in the Children's Hospital at Dartmouth's Pain Free Program, sits on her mother Tracy's lap as she awaits an MRI

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Small Patients, Big Pain

Ten million American children suffer chronic or recurrent pain. Treating them poses special challenges. Now doctors and researchers are learning how to help

By Karen Springen
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May 19 issue — At 9, Alyssa Ayala lives with constant pain, the result of a ruptured appendix four years ago. Nearly every day she suffers intense aches radiating from a three-quarter-inch-wide scar that runs from her bellybutton to her pubic bone. "It's as if Hercules were taking a stick and rubbing it hard against my tummy," says Alyssa. But with the help of massage, Iyengar yoga, biofeedback and low doses of the antidepressant Elavil and the anti-anxiety drug Effexor, she's beginning to feel better.

EVERY MONTH SHE travels nearly two hours from her home in Redlands, Calif., to UCLA's Pediatric Pain Program. She also recently started going twice a week to a free program at the First Nations Tribal Family Center in San Bernardino, Calif., where she learns to relax and focus by using her mind (not her hands) to operate a videogame-like biofeedback machine. Because Alyssa looks "normal," people often don't understand that she hurts so much, says her mother, Maria Isabel Ayala, a construction planner. "When they see a child not in a wheelchair or crutches or a bandage on their head, they look at the child as being fine."

But Alyssa is not fine, and neither are the estimated 10 million Americans 18 and younger with chronic or recurrent pain. They suffer from a variety of conditions: migraines, cancer, cystic fibrosis, sickle-cell anemia and nerve injuries from accidents or fractures. Until the mid-1980s, the medical community largely ignored their plight. Doctors thought newborns' immature nervous systems couldn't transmit pain and routinely operated on them without administering anesthesia (they used paralyzing agents, which left babies unable to move but still able to feel pain). But today, doctors are responding with strategies for managing discomfort in their youngest patients.

Scientists now know that there can be long-term consequences of childhood pain, particularly when suffered early in life, as the nervous system is developing. Studies show that babies circumcised without anesthesia feel more pain than their peers during routine vaccinations four and six months

later. But premature infants subjected to repeated painful procedures may actually suffer less pain later in life because hyperstimulation damages their nerve cells. “What the child ends up with is a pain system that is simply dysfunctional,” says K.J.S. Anand, a pediatrician at the University of Arkansas who chairs an FDA-National Institutes of Health “newborn initiative” task force for pain control. “It’s bad because these kids can get severe injuries and not report them.”

Armed with the new research, doctors are fine-tuning ways to measure discomfort in children. “There’s no pain meter,” says Dr. William Schechter, director of the pediatric pain-management center at Children’s Hospital of New York-Presbyterian. And unfortunately, kids can’t always describe how they feel. Two decades ago, doctors started using measures of behavior and pain such as the Children’s Hospital of Eastern Ontario Pain Scale (CHEOPS), which used indicators such as facial grimaces. Then in 1996, Canadian research nurse Bonnie Stevens and her colleagues developed the Premature Infant Pain Profile (or PIPP), which helps medical professionals identify the shrill cries, tightly closed eyes, wrinkled brow, rapid heart rate and thrashing movements of a baby in agony. Doctors also use the University of Michigan’s FLACC (for face, legs, activity, crying, consolability) scale for younger children. For older kids, there’s the Bieri faces scale. Children point to faces—from an extremely distressed one to a neutral one—to show which one best expresses their own feelings.

Such scales don’t work as well with children who have cognitive or neurological impairments, and researchers are working on better ways to assess their pain. When necessary, they can resort to more expensive, high-tech measures such as functional MRIs, which give a detailed picture of the brain. The problem: pain is subjective, so more activity in an area of the brain doesn’t necessarily mean that any given child feels more agony.

High-tech advances excite medical professionals, but so do low-tech ones. Children often thrive when they’re merely taught how to breathe deeply and use their imaginations to picture themselves in a pleasant place such as the beach or Disney World. “As they get involved in their imagination, their breathing slows down, their muscles relax, their heart rate changes,” says Dr. Lonnie Zeltzer, director of UCLA’s Pediatric Pain Program. “They’re learning how to use their imaginative self to change pain signaling.” With mood-ring-like strips that change color as fingers get warmer, children can see their efforts working. “You try to include as many of the different senses as possible—what are you hearing? What do you smell?” says Nancy Klein, author of “Healing Images for Children.” Kids also feel less anxious if doctors talk to them before a painful procedure and anticipate some of their fears. For example, kids may be scared of radiation because they know that’s how the Teenage Mutant Ninja Turtles were created. Parents can help by acting confident and calm—and by helping kids pack “relaxation kits” filled with comfort items such as a favorite stuffed animal.

Too few hospitals offer comprehensive pain programs for children. That’s no surprise: pediatric pain units are expensive to run. Insurance tends to reimburse for surgeries and medication, not acupuncture, hypnotherapy, yoga, massage and art therapy. But specialized treatment can have dramatic effects. At UCLA, pediatric art therapist and psychoanalyst Esther Dreifuss-Kattan gives kids acrylic paint and canvas paper. She doesn’t direct them to make pictures about their problems, but “often the pain comes up in what they do,” she says. Hypnotherapist Kathryn de Planque uses “guided imagery” to clear kids’ minds. To begin the process, she trains kids to think about green as a healing color and blue as a calming one. Then she gets them to imagine the colors becoming shiny helium balloons that “lift” them up. And Iyengar yoga instructor Beth Sternlieb helps kids with diseases like lupus and rheumatoid arthritis learn poses that soothe the nerves and build range of motion.

The dream for researchers is to create drugs so specifically targeted that they provide pain relief with few side effects. Dr. Charles Berde, director of the Pain Treatment Service at Children’s Hospital Boston, is testing new local anesthetics that could provide relief for up to four days. “The perfect thing would relieve all types of pain, be easy to use and easy to prescribe, that most people would be able to take, that would be quick-acting and long-lasting,” says Mathew Rudes, 16, of Northridge, Calif. Because of a rare condition called severe infantile Marfan syndrome that affects

every system in his body, he has suffered from pain since birth—at times feeling as though he has a stun gun firing on his back. Because his dream drug doesn't exist, he takes OxyContin, methadone and Valium. He tries to remain in the mainstream of life, which —includes school. For some kids, that seems impossible. Anna Dewey, 13, who now gets home-schooled, says her headaches feel “like someone’s hands are pushing in on my head really, really hard, and like my head is going to implode.” Despite trying heat, ice, massage and painkillers, she finds herself unable to sleep until 4 a.m. and sometimes unable even to chew food.

Doctors are also rethinking the treatment of acute pain for children who go to emergency rooms for more common injuries like broken limbs or cuts that need stitches. In the past, “you brought your kid to the hospital. They held them down and did something that hurt, and you brought them home,” says Joe Cravero, a pediatrician and anesthesiologist who is co-writing an American Academy of Pediatrics policy statement on pain relief in the ER. “It was like bringing your dog to the vet.” Kids who can't be calmed down easily may need a short-acting sedative such as Versed so that they won't remember the experience. “Sometimes just totally blunting the experience by wiping out their memory of it may be as positive as giving pain medication,” says Cravero. Emergency-room doctors are also distracting kids with everything from dolls to videos.

Many hospitals are finding that it helps to get the entire family involved. Lindsey Manzel, 16, of Omaha, Neb., suffered from reflex sympathetic dystrophy syndrome (RSD), a neuropathic disorder, brought on by a kick in the knee while playing soccer at age 11. The pain in her feet left her confined to a wheelchair. Last year she traveled to Milwaukee, where she spent two weeks in the pain program at the Children's Hospital of Wisconsin. “The pain stops you from being able to live your life—from moving, from touching,” she says. The Milwaukee program helped her and her family see how her condition affected her two sisters and her parents' relationship. Her younger sister, understandably, thought Lindsey got too much of their mom's attention. With the help of those insights, the family has returned to a more balanced life, and Lindsey now belongs to her school swim team.

Alyssa Ayala still dreams of a magical new drug delivered in the form of a watermelon-flavored lollipop. “The medication would be called ‘Cure’,” she says. “It would make the pain never come back.” Someday her wish may come true.

Kids Are Hurting, Too

Pain is something that people of all ages experience. Doctors' estimates help gauge the prevalence of pain among the 72 million Americans under 18:

- 5% Suffer from back pain
- 5% Endure facial pain
- 10% Suffer from migraines and severe headaches
- 12% Experience significant abdominal pain

In addition, the Centers for Disease Control say:

- 13,502 Americans under 19 are living with AIDS*
- 194,091 Americans under 25 have cancer, according to National Cancer Institute data*

* 2001