

The perils of "feeling no pain"

Anecdotes abound about autistic children so insensitive to pain that they show no reaction to burns, broken bones, or severe illnesses. Mary Coleman and Christopher Gillberg, for instance, tell of one seven-year-old boy who, while helping his mother in the kitchen, "put his hand down [on the stove] and did not remove it until the smell of burnt flesh attracted his interest," and of another autistic boy who snuck out of the house early one morning and played naked in the snow for more than an hour.

A new study by Kathleen Biersdorff of Canada suggests that such abnormally low pain sensitivity is common not just in autistic people but in developmentally disabled individuals as a group. Biersdorff asked relatives of 123 developmentally disabled individuals, and the staff members who worked with them, to report on how these individuals had reacted to painful injuries or illness. She reports that significantly elevated pain threshold was noted in a quarter of the individuals, and that "those with more severe mental retardation were ... more likely to display signs of pain insensitivity or indifference." The use of anticonvulsant or antipsychotic drugs did not significantly affect pain response.

A high pain threshold, Biersdorff says, can greatly increase the risk of serious injury. One of the subjects in her study, a 51-year-old woman, removed a hot pot from a stove wearing only rubber gloves; although the rubber melted onto her hands, she continued unperturbed with her work instead of seeking help.

Biersdorff says developmentally disabled individuals with life-threatening illnesses sometimes receive inadequate treatment because medical professionals mistakenly assume, based on a lack of "pain behavior," that their symptoms are mild. "The present study," Biersdorff says, "found instances where diagnoses of painful conditions had to be made on the basis of symptoms other than pain. A 20-year-old man with profound mental retardation and pica [the eating of non-foods] was taken for x-rays when his appetite diminished and a swollen abdomen was noticed. It was determined that he had eaten a plastic bag, which led to bowel obstruction requiring surgery. The typical signs of pain or discomfort were absent."

Activities that would cause most people pain sometimes are perceived as pleasurable to people with abnormal pain tolerance, Biersdorff says. She cites a case study of a 14-year-old retarded patient who begged a dentist to extract additional teeth because the sensation was so pleasant. Such altered pain perception may contribute to self-injury, although three of the eight self-injurious subjects Biersdorff studied had normal reactions to painful experiences.

One unusual reaction to pain often seen in developmentally disabled individuals, Biersdorff says, is hyperactivity. She speculates that an individual who becomes hyperactive during a normally painful experience "may be experiencing the sensation of pain

but is having difficulty interpreting its meaning (much as a chronic dieter may have difficulty distinguishing between hunger and emotional arousal)."

Biersdorff was surprised to find that pain insensitivity was rarely documented on patient files in the facility she studied, and that no effort had been made to instruct the patients themselves in identifying unusual symptoms usually associated with pain (rashes, burns, etc.) and communicating these problems to staff members. She suspects that even more serious problems will arise when such patients are treated by "generic" health practitioners unaware of how common abnormal pain sensation is in the developmentally disabled. With more and more disabled individuals living on their own in the community, she says, it is increasingly important to educate medical professionals about "the dangers inherent in using pain behaviors as a reliable indicator of medical need in this population."

"Incidence of significantly altered pain experience among individuals with developmental disabilities," Kathleen K. Biersdorff; *American Journal on Mental Retardation*, 1944, Vol. 98, No. 5, pp. 619-631. Address: Kathleen K. Biersdorff, Vocational and Rehabilitation Research Institute, 3304 33rd Street, N.W., Calgary, Alberta, Canada T2L 2A6.

Felbatol warnings

Individuals with uncontrolled seizures have been awaiting the release of the new anticonvulsant drug felbamate, known by the brand name Felbatol (see *ARRI* 8/2). But the drug's arrival on the market was followed, only weeks later, by reports that four patients taking it had died of aplastic anemia (a severe and sometimes untreatable blood disorder). Seventeen other cases of aplastic anemia linked to Felbatol have been reported.

As of press time the drug has not been recalled, and patients have been advised not to stop taking the medication without consulting their physicians. People taking Felbatol are advised to see a doctor if they experience heavy bleeding or easy bruising, or develop an infection or fever.

It is not yet known if the percentage of patients developing aplastic anemia will be higher with Felbatol than with other anticonvulsants, such as carbamazepine (Tegretol), which have also been linked to a slightly increased risk of the blood disorder.

Editor's note: DMG, which is unquestionably safe, sometimes controls "uncontrollable" seizures (New England Journal of Medicine, Oct. 21, 1982, pp. 1081-1082).

Melatonin studies spark hope, controversy

(continued from page 1)

Melatonin is secreted by the pineal gland, a tiny cone-shaped gland deep within the brain. It has been dubbed the "hormone of darkness" because at night, an area of the hypothalamus called the suprachiasmatic nucleus sends a signal to the pineal gland to secrete melatonin; in the daytime, little melatonin is secreted. Melatonin is involved in regulating circadian rhythms—patterns of activity associated with day and night, such as sleeping—and may also help control emotions.

In a study published last March, MIT neuroscientist Richard Wurtman reported that insomniacs given melatonin fell asleep within minutes. Sales of the hormone have skyrocketed since Wurtman reported his findings, but so have criticisms of Wurtman himself. While the synthetic melatonin used in research is available from health food suppliers, Wurtman is attempting to patent the use of melatonin to treat sleep disorders through Interneuron, a pharmaceutical company he co-founded. If he is successful, the hormone will be marketed as a sleep-disorder treatment only by prescription—a move Wurtman says will protect consumers.

"He's a very capable and distinguished scientist," Jonathan Rothschild, president of Cardiovascular Research, Ltd., told the *Wall Street Journal*, "but one has to look at any opinion that comes from him from the viewpoint that he's a major shareholder." One mail-order firm sells melatonin for about

\$24 per 400 3-mg tablets, far lower than the price would be if the substance were available only by prescription.

While Wurtman and opponents wrangle, researchers around the world are exploring melatonin's possible effectiveness as a contraceptive, a breast cancer preventative, and a treatment for Alzheimer's. It also appears to help night-shift workers and people suffering from jet lag.

Editor's note: While melatonin appears to be very safe in the short term, its long-term effects, especially on children, are not fully understood. In addition to controlling short-term cycles such as sleep-wake, melatonin is thought to control long-term effects such as seasonal mating instincts in animals, and the onset of sexual maturity (see *ARRI* 8/2, p. 7). If I had a child with sleep problems, I would try B6 and magnesium, and/or DMG, before trying melatonin (see letters in this issue). —BR

"The treatment of sleep disorders with melatonin," James E. Jan, H. Espezel, and R.E. Appleton; *Developmental Medicine and Child Neurology*, 1994, 36, pp. 97-107. Address: James E. Jan, Visually Impaired Program, B.C.'s Children's Hospital, 4480 Oak Street, Vancouver, B.C. V6H 3V4, Canada.

"Drug companies and health-food stores fight to peddle melatonin to insomniacs," Michael W. Miller, *Wall Street Journal*, August 31, 1994, section B, pages 1-2.

"The mysteries of melatonin," *Harvard Health Letter*, June 1993, Vol. 18, No. 8, pp. 6-8.