

# TRIALS AND TREATMENTS OF ANESTHESIA DOLOROSA

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The pain may not be as excruciating as trigeminal neuralgia, but anesthesia dolorosa can be just as troubling.

Some say this rare after-effect of TN surgery feels like a burning sensation in the face. Others say it's more like a prickling feeling.

At the same time, though, the area is dead to the touch -- a kind of incongruous combination of pain and numbness both.

"It feels like hundreds of bees are stinging my face and lips on the left side only," says June Tabor, an anesthesia dolorosa sufferer from Bluefield W.V. "My lips feel thick and swollen and they burn constantly."

"My left eye feels as though it is surrounded by little firings of pin pricks and the condition is constant," Is how James Leslie of Holmes Beach, Fla. describes his pain.

"It's a burning sensation, worst when I'm idle," says Larry Michelotti of Howard Beach, N.Y.

For Mary Halldorson of Charlotte N.C., there's a feeling of pressure in her eye to go along with pain, and it seems to get worse when the barometer drops or when there's a significant change in temperature, such as when she's near an air conditioner or standing over a hot stove.

And for Anthony Ferraiolo of Yonkers, N.Y., it's a troubling combination of pressure, heaviness and pain.

"My head feels like a bowling bowl," he says.

Though the descriptions are different, each is anesthesia dolorosa, one of the most dreaded complications of TN surgery. It's dreaded because medicine hasn't yet come up with a really good way to fix it.

Unlike TN, there are no two or three drugs widely regarded as effective. Rather, doctors try an array of drugs that cross over a variety of categories, including pain-killers, anticonvulsants, antidepressants, sedatives and narcotics. None, to date, have been found to be particularly effective.

On the bright side, anesthesia dolorosa is a very rare complication, and it's one that Cincinnati neurosurgeon and Trigeminal Neuralgia Association Medical Advisory Board member Dr. John M. Tew Jr. says usually improves with time.

According to case studies and TNA members with this condition, it's slightly more likely to happen as a result of the radio frequency rhizotomy procedure than other surgeries, but even then the incidence is only 2 percent or less.

Glycerol injections and complete or partial cutting of the trigeminal nerve are the second most likely surgeries to lead to anesthesia dolorosa (1 to 2 percent), while it occurs in only 1 in 1,000 cases or fewer with balloon compressions and microvascular decompressions.

"Fortunately, this is a very rare complication", says TNA President Claire Patterson. "Most surgeries are quite successful. But as an association we're trying to bring this problem into the foreground so more efforts can be made toward addressing it

Anesthesia dolorosa (sometimes called "analgesia dolorosa") occurs when the trigeminal nerve is damaged in such a way that the sense of touch is diminished or eliminated while a malfunctioning sensation of pain is left intact. That's possible because different nerve fibers perform different functions.

Anesthesia dolorosa pain is different from TN pain in that It's usually constant rather than intermittent, and it tends to have a burning or jabbing quality rather than the sharp, electric-like jolts of TN.

That's an important trait in telling the difference between true anesthesia dolorosa and a recurrence of T N pain with lingering numbness, says New York neurosurgeon Dr. Ronald Brisman, also a member of TNA's Medical Advisory Board. That distinction affects the course of treatment, he adds.

## **A CLASSIC, FIRST HAND DESCRIPTION**

Lisa Gregory of Pinellas Park, Fla., provides a classic description of anesthesia dolorosa: "I have a constant burning down my eye and across my cheek to above my teeth. It doesn't no away not like TN. It feels as if I

'Sometimes there's a heaviness or tightness across the same area, like a vice is across my face. At the same time, my face is numb. But I still have the constantly burning face that only I know is killing me."

Dr. Ronald Young, a Seattle neurosurgeon and TNA Medical Advisory Board member, says that although there is no single treatment that's 100 percent effective, there are many options -each of which has helped at least some people.

Dr. Young, for example, says he has had success using the anticonvulsant drugs carbamazepine (Tegretol) and phenytoin (Dilant-n), the antidepressant drug amitriptyline (Elavil) and occasionally some prescription pain-killers.

Dr. Brisman says he also has had success with amitriptyline and with the antidepressant nortriptyline (Pamelor.)

## **TWO FORMS OF ANESTHESIA DOLOROSA**

Dr. Steven Graff-Radford, director of the Head and Neck Section of Cedars Sinai Medical Center's Pain Center in Los Angeles and also a member of TNA's Medical Advisory Board, says he has found two different forms of anesthesia dolorosa.

He tells the difference by a diagnostic use of a thermogram (which measures minute temperature differences in the painful area) and nerve blocks of the sympathetic nervous system.

One form responds best to topical applications of the blood-pressure drug clonidine (Catapres) plus repeated nerve blocks, he says. In those cases he also uses a tricyclic antidepressant drug and-or a drug that blocks the brain's uptake of serotonin. His favorite two in those categories are, respectively, nortriptyline and paroxetine (Paxil).

If there is a sharp, shooting or electric component to the patient's pain, Dr. Graff-Radford uses some of the same drugs that are effective for TN, such as carbamazepine, phenytoin, baclofen (Lioresal), valproate (Depakote) or the new anticonvulsant gabapentin (Neurontin.)

For the other form of anesthesia dolorosa, Dr. Graff-Radford uses the topical anesthetic EMLA (which hospitals often use to numb the skin before inserting an intravenous line) along with the hot-pepper-based, over-the-counter cream Zostrix, typically used for arthritis. Has patients use these five times per day for five days, then three times per day thereafter.

"This should desensitize the region," explains Dr. Graff-Radford, adding that he also typically recommends nortriptyline and paroxetine for these patients as well.

Dr. Kim J. Burchiel, an Oregon neurosurgeon and TNA Medical Advisory Board member, says he's had success with the anticonvulsant clonazepam (Klonopin).

And he's also helped some patients with intravenous treatments of the anesthetic lidocaine, and most recently with IV treatments of Ketamine, a drug that affects how the brain processes pain signals. Dr. Burchiel says he believes "we will see great progress" in the future in developing tablet forms of such new-generation pain-relieving drugs as Ketamine.

"When all else fails," says Dr. Graff-Radford, "I feel that the use of high dose, long-acting narcotics may be of great significance."

"Psychological treatment may also be very helpful in dealing with anesthesia dolorosa," adds Dr. Young. "It may not reduce the intensity of the pain itself, but it certainly may be very helpful in assisting the patient in coping or dealing with the pain.

When drugs fail, Dr. Young says he has done thalamotomies and cingulotomies -- surgeries that selectively damage parts of the brain associated with pain sensation.

Another surgery that some surgeons try is the dorsal root entry zone (DREZ), a procedure developed by Dr. Blaine Nashold at Duke University. It also involves selectively damaging a part of the pain-transmission system at the back of the head with a Radiofrequency electrode.

## **SOME LEERY OF DREZ PROSPECTS**

Dr. Peter Jannetta, chief of neurosurgery at the University of Pittsburgh and chairman of TNA's Medical Advisory Board, says the success rate of the DREZ procedure is only about 50-50 at best, and it can produce some troubling side effects of its own, such as numbness or loss of coordination in the arms and hands.

"DREZ may be helpful," says Dr. Young "but my own experience has been that the success rate is low and the complication rate is extremely high so I recommend this only as the absolute last-ditch effort." Dr. Brisman concurs.

However, a 1994 research paper by Dr. Nashold and three other researchers at Duke reports that a new type of electrode has considerably lowered the limb problems to 33 percent of the cases while achieving pain relief for 70 percent of the 21 patients in the study.

When anesthesia dolorosa is the diagnosis, Dr. Young advises against any further TN surgeries designed to damage the trigeminal nerve itself, such as Radiofrequency rhizotomies or glycerol injections. "It's very important not to try destroying the trigeminal nerve root any more, he says, 'otherwise the anesthesia dolorosa can be made worse."

Among some of the other treatments that anesthesia dolorosa patients have tried with some success include: acupuncture, hypnosis, biofeedback TENS units, ice packs and various sorts of surgical nerve blocks.

"Sometimes just talking to others with the same problem may be helpful," adds Patterson.