



MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD LEADING EXPERTS

TRANSCRIPT



ARE MIGRAINE SURGERIES WORTH IT?

WILLIAM B. YOUNG, MD



Introduction (00:04): And you'll find that surgeons view this very different from headache specialists. You know, your migraine is going to be somewhere and the nerves for the outside of the migraine are going to be there. Occipital nerve blocks, where you give Novocain and you numb the nerve temporarily — they work for migraine. It doesn't mean that there's a disease in those nerves at all. Surgeons tend to interpret the response to nerve block as proof that you have a disease in the nerve of that area or the tissues of that area; headache doctors don't believe that. They believe that just blocking the nerve modulates the pain system, modulates the migraine system, and shuts down the migraine.

Kellie Pokrifka (00:52): For many of us with chronic migraine, we would do anything to get rid of the pain. Many of us have even considered surgery, but what do we know about these migraine surgeries? Are they safe? Are they effective? Can we trust the doctors or organizations offering these services? Is this another expensive promise of a cure with very little evidence behind it? To answer these questions some more is Dr. William Young. Dr. Young is a world-renowned pioneer in the field of migraine. He serves at the Jefferson Headache Center in Philadelphia. He instructs neurologists on headache medicine and consistently publishes research on the topic. He is board-certified in neurology, psychiatry and headache medicine. Dr. Young is a passionate advocate on eradicating the stigma of migraine. He fights on Capitol Hill for greater funding and research on this disease. And in addition to his roles at the American Headache Society and the American Academy of Neurology, he's also president of the Alliance for Headache Disorders. Dr. Young, welcome back to the Migraine World Summit.

Dr. Young (01:46): Thank you very much. Glad to be back.

Kellie Pokrifka (01:49): What type of surgeries are available for people with migraine?

Dr. Young (01:52): There are essentially four types of surgery. One, are stimulators that are tunneled under the skin and around the skull and stimulate various nerves, like the occipital nerve or the supraorbital nerve. The second type of surgery involves decompressing nerves around the head and sort of loosening them up. Sometimes, surgeons will cut the nerves and cause permanent damage and numbness in the area of the nerves that they've cut. The third type of surgery is plugging up a hole in the heart, a tiny little pinhole that a large percentage of people actually have normally — and that's called PFO (or patent foramen ovale) surgery — and you put a little device that sort of clogs up the hole. And then the fourth surgery that's sometimes done for headache disorders, and occasionally for chronic migraine, is called the Chiari surgery. And a Chiari malformation is: part of the brain is kind of sagging out of the skull area down into the area where the spinal cord is. And that surgery takes away the bone to relieve the pressure and make room for that abnormal dropping down of that part of the brain.

Kellie Pokrifka (03:22): Interesting. So, especially on social media, people may have seen the Reed and Omega procedures. What type of surgery is that?

Dr. Young (03:29): So those implant wires around the head. So the Omega is a little bit of an advancement on the occipital nerve stimulator, which just stimulate the occipital nerves behind the head that go on the back of the head all the way up to the top. And so this surgery sort of wraps the stimulating electrodes around the head in a 360-degree and gives more options for places to stimulate around the head, more nerves around the head. All of these surgeries involve wires under the skin on your head, tunneled to a battery and a



programming device that's in various parts — sometimes on the hip, sometimes under the shoulder of the clavicle in the chest. So those surgeries are done for some people with chronic migraine.

Kellie Pokrifka (04:30): And could you tell us a little bit about the heart surgery you're referring to?

Dr. Young (04:33): So, PFOs are tiny little holes in the heart that a certain percentage of people are born with naturally, and generally they have very little effect on someone through their lives. But people who have migraine with aura, in particular, have a very high rate of having those PFO holes in their heart. And there have been a number of trials of closure of those holes. And it's interesting: None of them have been positive, but if you add them all up together and do fancy statistics, it looks like it may help just a little bit for some people.

Kellie Pokrifka (05:14): So is there good evidence for surgeries for migraine?

Dr. Young (05:18): Well, there is ... it's sort of weak. First of all, doing good trials in surgery is very difficult. Do you do a sham surgery to see whether the surgery helped or just, it's a placebo effect? And placebo effects for surgery are very, very large. Is that all that these procedures are doing? The surgeons don't think so, but they're very controversial and most headache doctors believe that they're of very little value only for very rare patients — or for no one at all.

Kellie Pokrifka (06:00): Wow. Why are surgeries advertised for migraine?

Dr. Young (06:05): It's a profession. People do it, and you don't know if you've got a placebo effect or are you actually helping the disease? Maybe it doesn't matter. But you know, I think that patients like to tell the surgeons they're doing well, and the surgeons like to hear that. So it self-perpetuates.

Kellie Pokrifka (06:27): How much would a typical surgery cost?

Dr. Young (06:30): That, I have no idea, but it's expensive. It's tens of thousands of dollars, I would imagine.

Kellie Pokrifka (06:37): Can we talk about side effects or risks for surgery?

Dr. Young (06:42): Well, for the implantation of the wires and the electrodes inside the head and tunneling through the skin, there can be infections. The wires can sort of rub their way out from the inside out and then poke through the skin and get infected. Sometimes you can see, cosmetically, the wires across the forehead. And there's also a fair number of people who feel some kind of tugging when they move in certain directions with those wires in them. So those are all possible risks. The technology has gotten better and there's less of that now. Nonetheless ... overall the surgeons would claim otherwise, but most headache specialists believe that it'll help a few, some, but that the effect is not very great. Also, sometimes it works well for a while and then it stops working.

Kellie Pokrifka (07:49): So lead migration is one of the side effects. Would you need another surgery to correct that or would you just continue on with it?



Dr. Young (07:58): Most people will get lead migration. There's a little bit of give because they can program different parts of the electrode to stimulate. So if it migrates just a little bit, they might be able to compensate with the programming.

Kellie Pokrifka (08:13): And you said that most of them are connected to a battery. How do you go about charging the battery and how often would you have to do that?

Dr. Young (08:19): Well, it depends on the device. I think the modern technologies may be developing external charging, but eventually they run out and they have to be replaced.

Kellie Pokrifka (08:31): So there's a tingling sensation when the device is turned on. Is that bothersome?

Dr. Young (08:37): Mostly no. I mean, patients have the option to crank it up to a bothersome level, but by and large, my patients who've had these procedures have not been bothered by that.

Kellie Pokrifka (08:54): Do you have to stay overnight for the surgeries or is it quick? How long is recovery?

Dr. Young (08:59): Recovery is pretty quick; a few days. I'm not positive, but I don't think they're staying overnight, by and large.

Kellie Pokrifka (09:08): Are there any lifelong restrictions following the surgery?

Dr. Young (09:11): There's an issue with MRIs. So once you have wires in your head, MRIs may be problematic.

Kellie Pokrifka (09:21): How difficult is it to reverse surgery or remove any implanted devices?

Dr. Young (09:27): It's another invasive surgery and probably about as rough as putting them in, maybe a little less so. Most of my patients who've had it, have had it explanted. At some point it stopped working for them and they've wanted it out.

Kellie Pokrifka (09:44): "Most" is very significant.

Dr. Young (09:45): Oh, yes.

Kellie Pokrifka (09:47): Some address the supraorbital and occipital regions. Can you describe where that is and what symptoms may occur from that?

Dr. Young (09:54): So, the Omega device and other surgeons are putting electrodes under the skin on the forehead and getting the nerves that travel from the eyebrow north to the top of the head.

Kellie Pokrifka (10:08): And what nerve is that?

Dr. Young (10:10): The supraorbital and supratrochlear nerves.

Kellie Pokrifka (10:12): OK. And where are the occipital nerves?



Dr. Young (10:14): They're in the back. So, originally — the occipital nerves are the biggest ones — so doctors, surgeons started with them and now they put them all over. The Omega device goes around 360 and gets all the nerves. So it's advanced, since the simple occipital nerve stimulator devices.

Kellie Pokrifka (10:36): So if you're having issues with these nerves, how can you tell? Are there any telltale symptoms?

Dr. Young (10:43): That's a very controversial issue. And you'll find that surgeons view this very different from headache specialists. You know, your migraine is going to be somewhere and the nerves for the outside of the migraine are going to be there. Occipital nerve blocks, where you give Novocain and you numb the nerve temporarily — they work for migraine. It doesn't mean that there's a disease in those nerves at all. Surgeons tend to interpret the response to nerve block as proof that you have a disease in the nerve of that area or the tissues of that area; headache doctors don't believe that. They believe that just blocking the nerve modulates the pain system, modulates the migraine system, and shuts down the migraine.

Kellie Pokrifka (11:35): So if a nerve block is effective for you, that doesn't mean you have occipital neuralgia?

Dr. Young (11:39): Not at all.

Kellie Pokrifka (11:40): Interesting.

Dr. Young (11:41): And interestingly, if a nerve block is effective, it does not predict that the stimulator will be effective.

Kellie Pokrifka (11:50): Oh wow. OK. So are there any other treatment options for these nerves besides surgery or nerve blocks?

Dr. Young (11:58): Well, there are the decompression surgeries that surgeons are starting to do in various places around the country, and those are even more controversial. And you know, we've seen a lot of patients who've not been helped, who've come back with numb patches or multiple areas of surgery, with very temporary relief from that. The surgeons claim very high rates of success and cures and things like that, which the headache specialists don't see their patients receiving. And so you can argue that if you go get a surgery and you do great, you'll never go back to the headache doctor. You don't need him anymore, right? But that's not what we headache doctors are seeing.

Kellie Pokrifka (12:45): Is there a reason this nerve stimulation can't be taking place over the skin without requiring surgery?

Dr. Young (12:51): Well, there's absolutely no reason that stimulation doesn't occur on the skin. In fact, the Cefaly device does a very similar stimulation. It has two versions of it: One is a 20-minute prevent device and you put it over your forehead and it simulates the supraorbital and supratrochlear nerves in the front. And that stimulation is for 20 minutes a day, every day for the prevent. And for the acute, it's for an hour when you have a migraine attack.



Kellie Pokrifka (13:23): Is this stimulation comparable to the amount of stimulation or the amount of relief you get from the surgeries?

Dr. Young (13:31): I think it is. I don't think anybody has actually measured what the nerves are feeling and can say for sure. But my sense is that it is. And for those who are contemplating the 360-degree surgery with a frontal and the occipital electrodes, there will be, eventually in this country, a new device which will be a stimulator that you wear kind of like a crown. And it goes around the head and it can stimulate the occipital and the supraorbital, supratrochlear nerves.

Kellie Pokrifka (14:07): How far in the future are we talking for that? Is it a year, 10 years, 20 years?

Dr. Young (14:12): My guess is six to 12 months.

Kellie Pokrifka (14:15): That's amazing. And if you were to receive a surgery that stimulated those nerves, would that restrict your use of using neuromodulation devices that would also stimulate those nerves?

Dr. Young (14:26): Well, those are the neuromodulation devices. So the Cefaly device and the new Neurolief device, that may be coming in six to 12 months, my guess, are neuromodulation devices.

Kellie Pokrifka (14:43): So could you use one of those if you had received a surgery for those nerves?

Dr. Young (14:47): Ah. I don't think so. You know, you would have electrical stimulation that might transmit to the wires under the skin, and they'd be kind of doing the same thing in a way. Why would you do that?

Kellie Pokrifka (15:01): So many of these nerves are targeting peripheral nerves, which never go inside the brain.

Dr. Young (15:05): Right.

Kellie Pokrifka (15:06): If migraine is a disease of the brain, how would this help?

Dr. Young (15:10): Well, the surgeons believe that there's a type of migraine that's in the nerves outside the brain. The neurologists think that that's really not a major part of migraine, but that the change in the way the nerves are functioning modulates what's going on inside of the brain. So, you know, the black box that is the brain, those wires are those nerves going in. You stimulate those nerves in certain ways and you improve the function of the black box that is the brain.

Kellie Pokrifka (15:45): Why are we not able to permanently stop the activity of these nerves? Can we just not cut the nerve?

Dr. Young (15:51): That has been done. And I have many patients who come to me and they've had the nerves cut. And in general, they may do very well for a short period of time — and it always seems to come back.



Kellie Pokrifka (16:09): Interesting. So nerves can regrow?

Dr. Young (16:11): No. It's just that the brain compensates, and they're just left with a brain that functions as it did before and a numb spot on their head corresponding to the nerve that was cut.

Kellie Pokrifka (16:28): So these surgery-based organizations make a lot of claims. Which of those should we be wary about?

Dr. Young (16:36): You know, I am a neurologist headache doctor ... I think that their claims are not very realistic; they obviously feel very passionately about their claims. This is a hugely controversial area and patients should wade into it with a great deal of care.

Kellie Pokrifka (16:57): Do you provide surgery options for your patients?

Dr. Young (17:00): We have done occipital nerve stimulators. Most of my patients have been explanted, the device has been removed by now. A few still have it and claim a little bit of benefit.

Kellie Pokrifka (17:16): Is there an ideal candidate that you would recommend for surgery?

Dr. Young (17:21): Well, basically the people we send are pretty desperate. They failed all the pill preventives, the injectable preventives, and they go get a temporary device and then they respond. If they respond to the temporary device, which they can wear for, you know, a day or two or three, then the neurosurgeon will permanently put in a device. And put it under the skin and do it all sterilely so that they can wear the device indefinitely.

Kellie Pokrifka (17:56): Are there any risks with the temporary device?

Dr. Young (17:59): Less, because there's not enough time for a bad infection usually to develop. But obviously, you know, you have a wire coming out of your skin that's going under and around the skull. And there could be an infection; you could yank it accidentally; you can break the device. But if you're contemplating wearing or having an implanted device for the rest of your life, it's sometimes thought to be wise to have it for a temporary device first and worth the little risk of that.

Kellie Pokrifka (18:38): Is a temporary device or a temporary trial of the surgery available for all the surgeries you listed?

Dr. Young (18:45): I don't think for the decompression surgeries. For the nerve decompressions, you go in and the surgeons kind of look at what they see; and they do a decompression or some other surgery on the nerves if it looks like it's diseased, to their eye, and then close up the patient. So they'll make the decision during the surgery, exactly what they're going to do.

Kellie Pokrifka (19:15): So, with the decompression surgeries, I feel like a lot of migraine patients feel that everything on their head is very compressed; everything is hurting so badly. How do we know if that is something that we need to worry about?

Dr. Young (19:29): Well, surgeons will interpret a response to a treatment as that's the area that needs to be treated. So if they give Botox in an area and that's where the pain is, and



the patient feels better, then they may offer them the brow-lift surgery or they may offer them a frontal supraorbital nerve decompression; or if that's true in the occipital area, they'll offer them an occipital nerve decompression.

Kellie Pokrifka (20:00): So the idea that these surgeries aren't available at many hospitals is somewhat unsettling. So, I suffer from post-traumatic migraine, which happens after a brain injury. And patients like me are constantly hearing about concussion clinics or migraine centers that sort of promise to be a cure-all. And then they often don't offer much. How do we know whether we can trust these organizations? What sort of research should be done? How do we go in?

Dr. Young (20:27): I am not recommending these surgeries. So maybe you can interview someone who does them and who believes passionately that they're good for you. I think the people who benefit are rare, and the long-term benefit is smaller than what they're reporting, if there is any benefit. So, there are surgeons who passionately believe it, they get together, they try to improve their techniques. It doesn't make sense to most headache specialists.

Kellie Pokrifka (21:04): If a patient is considering the surgery, do you have any advice before they go into it?

Dr. Young (21:10): Try everything else. That's safer.

Kellie Pokrifka (21:14): Do you feel like we're on the forefront of new discoveries; that even patients who are desperate should hold off a little bit on doing this?

Dr. Young (21:22): I think that the pace of development of neuromodulation from the outside without surgery is pretty rapid. And so there are other choices that are coming, and having a permanent change in your body or damage to your nerves done by a surgeon may not make sense at this time when so many new treatments are coming.

Kellie Pokrifka (21:49): For the neuromodulation devices, which would be a sort of alternative, is there any risk of permanent modification or permanent damage?

Dr. Young (21:57): No, they're on the outside. And once the treatment's done, the device comes off and you're finished.

Kellie Pokrifka (22:05): So does the FDA or the AMA have any oversight with these surgeries?

Dr. Young (22:11): Not really. The devices are not specifically for the surgery for migraine and they're cleared, in general, for nerve stimulation. And the criteria that the FDA uses is much laxer than, say, a pill.

Kellie Pokrifka (22:38): So there's no real oversight with these.

Dr. Young (22:41): Essentially, no.

Kellie Pokrifka (22:42): How does insurance coverage usually work for this?



Dr. Young (22:46): I wouldn't know. My patients have, in general, gotten coverage and had to fight for it. I don't think they've paid out of pocket. But I don't know if all of them have been able to get it. I think some of my patients have wanted the surgery and been unable to get the stimulation surgery because of insurance companies.

Kellie Pokrifka (23:08): So with any type of surgery, it's usually better to get a second opinion. So if a patient goes into one of these centers and the physician says, "You're a great candidate; this will provide a great benefit to you," how would a patient go about getting a second opinion?

Dr. Young (23:23): And that's a tricky question because the attitudes towards the surgery, the beliefs about it, are so very divergent and there's so much controversy. So I would say go to a headache specialist, somebody who's trained and certified in headache medicine, and talk to them and see if it's reasonable, in your particular case, to take that big step.

Kellie Pokrifka (23:51): Are the benefits of the surgery — if a patient does get benefits — are they generally lifelong or do you have to go back and touch up the surgeries to get them removed?

Dr. Young (24:01): The patients that I've seen who've had the decompression surgeries have, on occasion, had touch-ups. And then the patients who've had implanted devices have sometimes had to have revisions; and then for most of them, eventually it stops working well. And then they've been explanted.

Kellie Pokrifka (24:20): Do we have a general time period on when the device typically stops working?

Dr. Young (24:26): Well, the device will last for years. One of my patients, I think after eight or 10 years, is having her battery replaced. But many have had problems along the way at any point, when they've gotten an infection, or the electrodes have eroded, or other problems have developed.

Kellie Pokrifka (24:53): To get the battery replaced, does that require another full surgery?

Dr. Young (24:56): It's a smaller surgery, but it is surgery. Yes.

Kellie Pokrifka (24:59): And is there a daily charging of the batteries or is that just something that's not a possibility?

Dr. Young (25:04): I think it's changing. I believe it's a daily charging now, but I'm not really up. I haven't sent anybody for a device in several years.

Kellie Pokrifka (25:13): What does it mean when the leads migrate?

Dr. Young (25:16): So the leads are tunneled under the skin, and they are in and around the small nerves that are coming under the skin to the outside of the head, to feel things for the outside of the head. And they can move. And so you've programmed it just so, so that the electricity is hitting the nerve in exactly the right way and the right amount. And then there's a tug, or you sleep funny, and it just moves a quarter of an inch or half an inch and it no longer works very well.



Kellie Pokrifka (25:52): How precise does the location have to be for the leads?

Dr. Young (25:57): It's not too precise because the leads themselves have lots of different spots on them. And then you generally use the computer to sort of stimulate each one and see what it does and program the leads to do their job.

Kellie Pokrifka (26:12): You mentioned the Chiari malformation surgery. Could you explain that one?

Dr. Young (26:16): A certain percentage, a small percentage of people — maybe a couple of percentage of people — are born with that saggy part of the back of the brain. The cerebellum is just dropping a little bit too low into the area where the spine starts at the base of the head. And that causes a certain kind of headache, which is a cough headache and it's a very specific thing. And when somebody coughs, they'll get an explosive pain and they'll shoot from the back of the head. And they may get some neurological symptoms, and some numbness and tingling in their face, or some tongue problems because there's certain nerves that come out from that area. And the surgery is really quite effective for those problems, and you have to make a little bit more space and take away a little bit of the bone around the space so that there's plenty of room for that sagging part of the cerebellum. But what's happened is, many surgeons have been doing it for chronic migraine. So they'll identify somebody with chronic migraine who doesn't have a cough headache and whose chronic migraine hasn't responded. And they say your problem is from the Chiari. And then the patient goes in for the Chiari surgery and doesn't get better.

Kellie Pokrifka (27:44): So there's no way to check if you have that malformation?

Dr. Young (27:47): You can get an MRI and it'll show the malformation very well. The issue is, is that malformation — which is so common in normal people — is that causing the headache problem that you have?

Kellie Pokrifka (28:01): And let's discuss the cough headache. Is that the only time that they will get pain? And also, if you do get a migraine when you cough, does that mean that you have the Chiari malformation?

Dr. Young (28:11): Well, most people with migraine don't like to cough. They don't like to strain or bear down. And that's the other trigger for the cough headache, is straining, or moving something heavy, or really tightening up the muscles of the belly. And that's the specific type that responds. The chronic migraine doesn't. I've had one or two patients who had cough headache and chronic migraine, and the chronic migraine got a little bit better as a result, and the cough headache went away, completely cured. But I do not recommend Chiari surgery for people with chronic migraine who have a Chiari and they don't have the cough headache.

Kellie Pokrifka (29:03): Are there any risks of living with this malformation and not getting surgery?

Dr. Young (29:08): If the malformation is very big, causing a cough headache or those symptoms around the mouth and tongue, there can be some spinal cord damage. But that's from a very big Chiari, and is different than a headache problem. That's a Chiari problem.



Kellie Pokrifka (29:25): And would that be very obvious on an MRI, if it was that big, that you would definitely need the surgery?

Dr. Young (29:31): Oh, yes.

Kellie Pokrifka (29:31): So, Dr. Young, do you have any final thoughts on migraine surgeries?

Dr. Young (29:35): It's a really controversial area and there's a lot of argument between the surgical people and the headache people. And you'll find very different opinions in both camps.

Kellie Pokrifka (29:53): All right, wonderful. Thank you so much, Dr. Young.

Dr. Young (30:00): Thanks.