



INTERVIEW TRANSCRIPT

DISCUSSIONS WITH WORLD-LEADING EXPERTS

Why Isn't There a Cure for Headache Disorders?

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Introduction (00:04): How many times have we been asked, “Why isn't there a cure for headaches that plague us?” Our next guest spent years exploring the scientific frontiers to shed light on this mysterious and excruciating condition that we all share. And what he's learned has been eloquently captured in a new book titled *The Headache: The Science of a Most Confounding Affliction and a Search for Relief*.

Introduction (cont.) (00:31): Former *New York Times* reporter and editor Tom Zeller Jr. is an award-winning science journalist whose work has been also featured in *National Geographic* magazine, *Bloomberg*, and *Forbes*, among other publications, including *Undark* magazine, where he is the editor-in-chief. We'll talk about what he's learned, what gives him hope, and how the landscape of migraine and headache care is finally beginning to change. Tom Zeller, welcome to the Migraine World Summit.

Tom Zeller Jr (01:00): Thanks, Paula. It's great to be here.

Paula K. Dumas (01:03): Wonderful. Well, what a read this was from the history of headaches to the future, and I found it to be raw and profound and witty and hopeful. So, after thousands of news articles published, what inspired you to make headache the topic of your first book?

Tom Zeller Jr (01:22): Well, I should say at the outset that it was not something that I ever really planned to do. I'd never written about headache publicly, and in fact, I'd never even covered medicine or health in my roughly 30 years as a journalist. I mostly covered environmental issues, energy development, general science stuff, a bit of business and technology.

Tom Zeller Jr (01:46): But when I started to get serious about thinking about writing a book, I realized that there was one thing that I had been researching most of my life, and that was headache disorders. Mostly cluster headache, because that's what I have. So, while I only started working in earnest on a book a few years ago, I think that I'd actually been working on this book for most of my adult life.

Paula K. Dumas (02:11): Right. And as a person with migraine, I found so many interesting facts in this. Even though I've been researching headache for my whole life, and I've been researching migraine intensely for the past 11 years, I learned a lot from this book, and I think everybody will. So, what excited me was that a book like this that's published by HarperCollins — for those who don't know publishers, HarperCollins, really big, one of the big four — it's big news for the headache field. So, what impact do you hope that it has on public and media awareness?

Tom Zeller Jr (02:44): I think, to be honest, that I had no idea when I started out that headache science was as orphaned, I guess you could put it, as it actually is until I started digging into it. So, coming from the perspective of someone who has cluster, which is extremely rare, I sort of resigned myself to the fact that the dearth of science on the topic was commensurate with the incidence of headache.

Tom Zeller Jr (03:09): I was just unlucky to have a disorder that affected less than 1% of the population, and it would be ludicrous of me to expect that interest, or really dollars, would flow to this disorder given so many other impactful diseases out there.

Tom Zeller Jr (03:23): But when I started to peel back the layers on the underlying biology, when I came to understand that the lack of scientific interest extended to migraine too, which, as you already know, impacts tens of millions of people, it struck me that it was more than just bad luck that was holding things back.



Tom Zeller Jr (03:45): So, I guess, if anything, I hope the book exposes a few things about how science gets funded and maybe opens up a conversation about the neglect that headache disorders, writ large, have historically endured.

Paula K. Dumas (03:58): Every time I see this book covered by *The New York Times* or *The Wall Street Journal*, I get really excited because it maybe will promote a conversation that reaches just the right person. So, let's talk about you for a minute. When did your cluster headaches first begin, and how did you make sense of them before you had a diagnosis?

Tom Zeller Jr (04:20): As is very typical for cluster headache, they started for me in my early 20s. I didn't put this in the book, but I think the very first one that hit me, if I were to trace it, was when I was 20 and I was living up near the Arctic Circle, actually, in rural Finland. I was teaching English to little Finnish kindergartners.

Tom Zeller Jr (04:40): And at some point during a recess period, I was sitting on one of the tiny little kindergarten tables and watching the kids play, and an incredibly sharp pain just suddenly rose up in a matter of seconds right behind my right eyeball. And I stumbled to the bathroom as quickly as I could and just immediately slipped down to the floor, clutching the side of my head, and easily the most painful thing that I'd ever experienced to that date.

Tom Zeller Jr (05:09): And unlike a typical cluster, what I would learn about clusters later on is that it didn't last very long. It was maybe like a minute. And then poof, it just evaporated. And I was fine. As is my want, I immediately began chalking it up to various things, maybe just a freak anomaly. Maybe it was something I ate or drank the night before. And it didn't really happen again for another year or so after I was back in the U.S.. And by that time, I was actually working in a library.

Tom Zeller Jr (05:40): So when I started to get my first classic cluster attacks, it was my inclination to immediately go to the medical stacks and look it up. And in some ways, cluster is more forgiving, I think, in that way compared to migraine, because the symptoms are just so singular and with very little variation from patient to patient. So even these dusty medical stacks, I could immediately recognize: I have cluster headache without even going to a doc. So that would have been like in the mid-1990s.

Tom Zeller Jr (06:10): So I was able to sort of take that information and, you know, there was this new thing called the internet. And there were already forums there where people were talking about things like cluster headache. And so I started to initially self-medicate using some of the recipes that I would find on these forums. And then by the time I actually got to see a real doc and sort of explain what I was going through, Imitrex was just coming onto the market.

Tom Zeller Jr (06:39): And that was a godsend, as the book will attest. And I just sort of muddled through life using the Imitrex and a combination of other hand-me-down drugs that are typically prescribed for cluster headache, all of which have terrible side effects, as you know. It's a common tale. But yeah, that's sort of how it all began for me.

Paula K. Dumas (07:02): Yeah. And I think a lot of people have a similar arc. You know, there's the self-blame, then the detective work, then the trying to navigate the system, dealing with bad treatments, and reaching out for help wherever you can find it. Now you held a pretty high-powered role at one of the world's leading news organizations. How did you manage cluster attacks in such a demanding environment?

Tom Zeller Jr (07:29): Yeah. Well, I got at this a little bit in the book, but I like to think of those years when I was sort of building my career inside *The Times* as a period of vigorous advance and then strategic retreat, which, cluster headaches being what they are, at least in the episodic version,



which is what I have, you get periods of respite where the headaches just sort of go away and you can go months, maybe even a year without having attacks.

Tom Zeller Jr (07:57): So when my clusters were in remission, I worked really hard. I moved my way around the newsroom and up the ladder. And then when they came back, I would sort of shrink to a corner. I would avoid or forego opportunities, working from home when I could, making excuses, and basically hiding as best as I could.

Tom Zeller Jr (08:20): And hiding, I think is important. It's a big thing in the book because at least for me and for a lot of patients I talked to, it was important to hide my condition from people for reasons that I think we'll probably get into. But I did not want to be considered whatever the prevailing, the ambient judgment was of the day, whether it was like, I didn't want to be considered weak or in some way compromised.

Tom Zeller Jr (08:42): I certainly didn't want to be considered overly dramatic, or God forbid, that I was faking it. So I really tried to sort of downplay it and hide it. People in my life knew, of course, but I did not want my employers to know. And most people that I worked with would be surprised to learn that I was going through this.

Paula K. Dumas (09:01): Saying, yeah, there's the politics of the workplace. And then there's your job and the accuracy that's required. And people questioning your competence when they know that you're dealing with something that is as distracting as acute pain can be.

Tom Zeller Jr (09:18): And that's if you're lucky enough for someone to sort of accept that you *are* in pain. And you know, as we know, many people don't.

Paula K. Dumas (09:25): So I loved following your journey as you sought care from the top headache experts and you even joined clinical trials. And I was fascinated when you turned to a less credentialed physician that you called Dr. Wilford Brimley. I had to explain who that was to one of my colleagues who is a little bit younger. What drew you to that experience with Dr. Brimley, as we'll call him, and what did it teach you?

Tom Zeller Jr (09:53): In terms of, you know, timeline, he really was kind of the first doctor that I brought these headaches to in any meaningful way. And I had selected him as my primary care physician because he was practicing in a little clinic in Queens, New York, which was not far from my apartment in Astoria. And, as the book lays out, he was a character in a lot of ways. He wasn't the best doctor. He got himself into some serious trouble.

Tom Zeller Jr (10:26): And he never seemed to remember from one visit to the next that I had cluster headache. He always called it migraine. As he would sit there and kind of dictate into his little machine right there in front of me, I've distinct memories of him saying, you know, "middle-aged male, apparently healthy, complaining of migraine." And I took umbrage both to migraine and to him calling me middle-aged at that time because I was only in my 30s.

Tom Zeller Jr (10:49): But I had to correct him every time and say, you know, "No, it's cluster headache." And he would sometimes even ask, "Are you having a headache right now?" Which is laughable because anyone who has seen someone in the throes of a cluster headache will know that they cannot sit still. They can't really even speak. They're probably on the floor writhing around or banging their head against something. This is the upside.

Tom Zeller Jr (11:11): I mean, he was very open to literature that I would bring in in my late-night sort of research. And that includes a lot of really prominent research. I remember bringing, before I ever even knew who Peter Goadsby was, bringing a paper written by Peter Goadsby to Dr. Wilford Brimley and saying, "Here, look at this, look what this guy is doing. Look at this explanation."



Tom Zeller Jr (11:35): He was also more than willing to hoard these expensive new Imitrex injections that Glaxo representatives would bring to his office and he would hoard them specifically for me. And he'd also go to battle with insurance companies. I don't know if you remember, but those Imitrex injections could be as much as \$900 a pop. And so it was really just out of reach and he would get on the phone and harangue my insurance company on my behalf.

Tom Zeller Jr (12:02): And I would later go to see more advanced doctors and highly regarded specialists and they were certainly more knowledgeable than him, but at the same time there wasn't much more that they could do for me than Dr. Brimley was already doing.

Tom Zeller Jr (12:18): And the fact is that most of us, and I had learned this in the course of reporting the book, given the absolutely tiny number of headache specialists in the world, will need to rely on our primary care docs as our medical companions on this journey. So, if there's anything I learned in speaking to dozens of headache patients, it's that educating generalists, educating primary care physicians is perhaps the most important avenue to getting better care.

Paula K. Dumas (12:47): It really is critical. And I think many people in our community wind up with doctors who have more empathy than expertise, or in your case, memory of what your condition was, right? And you go in and it was perfect because you were an advocate for your own care. You're like, "Here's the research, here's what's going on. Let me just remind you again, and here's what I need." And together you worked it out. So I can see why you stuck with him.

Tom Zeller Jr (13:20): It was a bit of a marriage of necessity. I mean, there wasn't ... I think I mentioned in the book, I did seek an opportunity to see a neurologist in New York City, but the waitlist was, you know, they couldn't see me for many months. And as you know, a cluster headache attack usually only lasts for a month or two anyway. So I would have nothing to show or say to this person by the time I got to see them. This is the conundrum that a lot of people in this position face.

Paula K. Dumas (13:44): You talked about hiding and we all know that headache is an invisible disorder. So what toll do you feel that that invisibility takes on patients seeking validation or care?

Tom Zeller Jr (13:55): We all long for evidence. We're visual animals, first and foremost, I think. So there is a natural inclination when someone is in pain or suffering to look for a telltale sign: a break, a bruise, a tear, a rupture, something that we can point to and say, "Ah, there, there's the pain that's right there." We don't have that with headache disorders. Not really. There's some small things. Imaging studies now can show brain activation in certain areas.

Tom Zeller Jr (14:27): We know now through some nifty studies that certain neurochemicals are elevated during an event, and with cluster, there's some physical signs: a drooping eyelid, a leaky nose, that comes along with the pain, but still the most salient thing, that grinding pain, and the source of that grinding pain is just not visible to onlookers. And so unless you have experienced one of these disorders yourself, you can't know.

Tom Zeller Jr (14:57): So those of us with these disorders, we really only have our testimony. And I don't need to tell you that sometimes that testimony is met with suspicion, met with a sense that perhaps we're being melodramatic or hyperbolic, that we're seeking attention or maybe an excuse for something. And there's always going to be a certain psychological toll to all that. So I think that's sort of like what is unique about not just migraine or cluster headache, but any invisible pain disorder. We only have our word, and that's a tough lot.

Paula K. Dumas (15:34): Yeah. And when you're going in to see a doctor who is seeing a lot of different patients and they may not remember you and they may not, you know, their records might not be that great depending upon what they have access to, the continuity of care becomes an issue. And with GPs, if people are relying upon GPs, and many, many are, the credibility comes into play.



So what's it going to take for the medical establishment and society to take headache disorder seriously?

Tom Zeller Jr (16:09): Wow. Well, it's a tall order. I think better education in medical schools would be one great place to start. I was shocked to learn how little time is spent in med schools, even on the neurology track, discussing headache disorders. I talked to students who were in medical school at the time I was interviewing them and they're like, "Yeah, we spend about 10 minutes on the topic." It's not considered serious. It's not considered important.

Tom Zeller Jr (16:38): I also think forums like this one are key. They provide such a powerful and potent connection between the patient community and the expert community. And that interaction can then distill down into the clinic and inform the interactions that patients have with their own doctors. I also think just keeping the conversation going and keeping it public, it really matters.

Tom Zeller Jr (17:03): I don't think it's true of everyone, but a lot of us, as I've said, hide for all the reasons we already talked about. So, we don't want to be considered a faker. We don't want to be disbelieved. So we hide it. And that was partly why I was, honestly, reluctant to do a book about headache disorders. I realized at some point that I'm going to have to become naked with this. I'd have to go public with something that I'd spent most of my life hiding, but that's untenable at some point. And nothing would ever change if I continued to hide and if everyone else continues to hide. So I think being willing to just talk about this stuff out loud, in forums like this, but also in your everyday life, despite the judgment, despite the stigma, despite the biases, that's important too. And I think that will help to change things as well.

Paula K. Dumas (17:56): Well, I think every patient watching this and many physicians are cheering you on because it does take a lot of courage to be as "naked," using your word, or raw, about what you experienced. I'd like to take a minute and ask you just to read a little segment from your book about your experience with a particularly low point in your cluster journey.

Tom Zeller Jr (18:24): OK. I think you're talking about the night of the train.

Paula K. Dumas (18:29): The night of the train. Yeah.

Tom Zeller Jr (18:30): So that was a night that occurred during a particularly dark period with the clusters. I was getting repeatedly hit with attacks over and over. I was working mostly from home. I was down to my last Imitrex injection, which I was preserving for a time when I absolutely couldn't hide. So, and I was, alongside that, taking lots of other of the sorts of, as we know, hand-me-down medications that were sort of the standard treatments for the time. One of them being verapamil, which is a calcium channel blocker, lowers the blood pressure. I was taking steroids. I was taking magnesium. I was taking all kinds of stuff. I was inhaling capsaicin to try and blunt the pain. I was in bad shape. At some point I just stopped paying attention to what the recommended dosage of verapamil was. And I didn't care. I just was going to continue taking it until the attacks stopped.

Tom Zeller Jr (19:34): And that's sort of where I think this passage picks up. So I'll begin reading here: *I wasn't thinking about caution anymore. I'd long ago blown past caution. I just wanted the attacks to stop. I needed the attacks to stop. I had these pills and I was going to take them until the attacks stopped. The noise started as a low rush, like the thick displaced air of a distant, the fast-approaching engine.*

Tom Zeller Jr (20:04): *It wasn't the familiar rattle or hum of an elevated end line, which passed a few blocks to the west of my windows, but the gathering storm of a locomotive. I recall thinking little of it at first. And I continued my brushing routine, staring thousands of miles across the emptiness into the sink's black drain hole. If I was contemplating the next day's A-1 laurels, for example, or worrying that we'd gotten something wrong, I don't remember them.*



Tom Zeller Jr (20:29): *All I can conjure is that train, far away at first, and then gathering in intensity, rising to a roar as if for all the world, I was straddling the tracks.*

Paula K. Dumas (20:39): As you continue to explain what happened this particular evening, where did it end up?

Tom Zeller Jr (20:46): Well, so, yeah, I was at the sink brushing my teeth and I clearly ... I didn't know at the time, but I had taken way too much of verapamil and all I remember is sort of stumbling. I heard this *whoosh*, this loud roar — I call it the train — in my ears. It sort of filled until the point where it was almost like a hurricane sound in my ears. And I stumbled out of the bathroom, maybe lurched a few steps forward and then I don't really remember what happened after that. I blacked out.

Tom Zeller Jr (21:15): I woke up sometime later on the bedroom floor, bleeding from the side of my head. I had clearly fallen like a rag doll. And, in my subsequent research, I clearly came to understand that I had lowered my blood pressure to a very dangerous point. My heart was not pumping enough blood to even get into my limbs at that point. And so I was sort of paralyzed and pressed down to the ground. I woke up and I was aware of where I was, but I really couldn't move.

Tom Zeller Jr (21:48): I mean, I just couldn't even summon the ability to move my limbs. And from that point, I just sort of faded in and out of consciousness. I, eventually over hours, managed to get myself into bed. And I woke up the next day with blood on the pillow. And the thing that I sort of took note of in the book that still sticks with me is that I, you know, I wasn't afraid of that moment. I wasn't afraid of what I'd done, even.

Tom Zeller Jr (22:18): I was just really happy that I had slept for the first time in a very long time for a sustained period. And that sort of was a wake-up moment for me that, you know, I needed, I needed help.

Paula K. Dumas (22:34): I'm glad you got better help. I mean, for people who don't understand migraine and don't understand cluster, to me, that episode shows, really, the degree of our desperation to get relief and to get sleep that others will never understand.

Tom Zeller Jr (22:53): I felt powerful in that I had reached inside and done something where nothing seemed to alter. I couldn't get inside that anatomy of myself in order to make a change. And even though this change sort of brought me to the brink, almost to the point of death, I felt empowered just by that moment of being able to get in there and just mess things up a little bit. It was a completely unhealthy way to think, but this is, again, this is the desperation that people feel.

Paula K. Dumas (23:22): On your quest, you traveled to Copenhagen, New Haven, Houston, L.A., and beyond to interview experts in the field, asking a number of provocative questions. So what was one of the most astounding things that you learned through your research?

Tom Zeller Jr (23:36): I think it's almost certainly the fact that there's so little known about headache disorders. I was probably naive going in, but I assumed that we at least understood the anatomical choreography underpinning a migraine or a cluster attack.

Tom Zeller Jr (23:53): I understood that effective treatments were still elusive, but I assumed that the medical and scientific communities had at least agreed, or they could agree on the basics of what's going on inside a person's head when they're in the throes of an attack. But as the book makes clear, that's simply not true. And there's actually a lot of disagreement about what's going on inside our heads.

Tom Zeller Jr (24:20): I was also sort of dumbstruck by the fact that so many scientists who would tell me this out loud and doctors and researchers who devote their lives to this topic, who make



getting to the bottom of these disorders their life mission, were in fact discouraged by their mentors in school from taking this path. They were literally told that headache disorders are not serious business, that the patient community is a drag, that there's no money in it.

Tom Zeller Jr (24:48): So don't bother; do something more important with your career. So given the disability burden that we all know is associated with these disorders, it's incredible that this disposition is still at work inside the medical establishment itself. I was completely blown away by that.

Paula K. Dumas (25:05): Yeah. I found that shocking as well to learn, which makes me even more grateful to each of the experts that has devoted their career to this space for something that's disabled all of us.

Tom Zeller Jr (25:18): Absolutely.

Paula K. Dumas (25:19): So you also dug into some of the current treatments and some of the new directions in treatment. What gives you the most hope for people with severe headache disorders?

Tom Zeller Jr (25:31): Yeah. I mean, I think that there was, there has been a bit of a sea change. We all know the CGRP [calcitonin gene-related peptide] medications, the inhibitors that came out in 2018. And that was sort of a really pivotal moment. It sort of signaled that there are some pretty sophisticated targets that scientists can take a look at as a way of interrupting these cycles of pain.

Tom Zeller Jr (25:57): So, there are now lots of other neuropeptides that are being explored as potential targets too. I'm sure these come up in your conversations. PACAP [pituitary adenylate cyclase-activating polypeptide] is one, VIP [vasoactive intestinal peptide], and there's a whole alphabet soup of others. The work out of Denmark looking at potassium channels I think is pretty exciting.

Tom Zeller Jr (26:22): And I also think that the device ecosystem is kind of interesting. I don't personally have any experience with these neuromodulation devices and all the different flavors that are out there, but they're growing. And some patients that I've spoken to have found relief through them, and pretty good relief. Now, does it last? Does it always work? I don't know. But, you know, from my point of view, whatever works for you is fabulous.

Tom Zeller Jr (26:44): And if device makers are out there trying to find ways to interrupt that signal processing through neuromodulation, I'm all for it. I think it's great. So I think there's a lot of percolating activity on a lot of different fronts. And if someone suffering out there needs an amulet of hope, I think that would be it. There are people working hard to try and get to the bottom of this.

Paula K. Dumas (27:11): There absolutely are. Well, one of the stories that you tell, you interviewed a number of different people with migraine and cluster headache for this book. You did a retelling of Will Erwin's story and his family's experience. I found it to be both dramatic and touching. Can you share a bit of that and how it marked you?

Tom Zeller Jr (27:33): Will Erwin, whose name is now associated with a headache research center in Texas, was a young man who suffered from, among other things, cluster headache. And he was suffering from cluster headache at a time when there were far fewer treatments available and he could not find help. He experimented with psychedelics. He experimented with almost any possible remedy he could find, but nothing worked.

Tom Zeller Jr (28:09): And his family was even generous enough to send him to some great doctors up in the Northeast and to spend time exploring the best possible treatments. Nothing worked, and



eventually it became too much for Will and he took his own life. He took his own life in a way that ... no parent should have to go through this.

Tom Zeller Jr (28:39): His mother found him. It was a very public event and I still get choked up when I think about it because it was, it captured — I saw something in Will's story and I saw something in his mother's retelling of the story, which they very generously shared with me when I went down to visit with them, in great detail. I saw in Will myself as a younger person and, yeah, I think I knew what he was, what he was feeling.

Paula K. Dumas (29:17): I did. I mean, I got choked up when I read that chapter and I thought about Will on the ground and I thought about you on the ground of your apartment. And I thought about me and being in the fetal position on my cold bathroom floor. I think we can all relate to it and it's what propels us forward as advocates and educators. And, yeah, so, so I found it to be very moving and I hope that that is a story that we all take with us for both comfort and fuel.

Tom Zeller Jr (30:00): Yeah. Yeah. And I think we all owe a little something to Will and to his family for sharing their story. And, you know, they took that and they've put money behind a research organization there in Texas. There can't be enough of them. And so to take that experience and to take that loss and translate it into something that's trying very hard to make sure that no one ever has to go through what Will went through, I think we owe them a debt of gratitude and I'm really grateful.

Paula K. Dumas (30:31): We do. Thank you to the Erwin family for that. So as both a journalist and a patient, how has this journey changed the way you think about pain and hope and the human capacity to endure?

Tom Zeller Jr (30:46): Because there are so many more migraine patients, I spent a lot of my time researching the book with people who have migraine, less than with people who have cluster, and the level of resilience that I encountered among this community of migraine patients in particular was just so ennobling and so inspiring to me that, you know, there are a lot of people who are far worse off than me. And I don't like to get into a game of comparing people's pain, comparing people's experience.

Tom Zeller Jr (31:18): Any sort of pain is a drag on your life and it all is worthy of respect. But I do have to say that, you know, I talk to people who have persevered through all kinds of trials with their migraine and raising a family and maintaining a job, and despite all odds, maintaining a spring in their step despite all of that. And I have to say that, knowing that there are people out there like that — we can't all be like that all the time.

Tom Zeller Jr (31:56): It gets to all of us sooner or later, but talking to those people really, really, it showed me a sort of grace in the face of great pain and great challenge that I now try to emulate, and I think if anybody out there is looking for role models or looking for inspiration on what resilience looks like, they'll find a lot of that in the book.

Paula K. Dumas (32:22): No doubt. No doubt. Well, thank you so much, Tom. Again, Tom's book is called *The Headache*, and there's a link to pick up a copy below this talk, and I hope that you do. Tom, where else can we learn more about what you're doing and follow your work?

Tom Zeller Jr (32:39): Sure. Yeah, you can find me. I have a website, tomzeller.com or tomzellerjr.com. They'll both get you there. And if you want to follow me on social media, I'm not that active on social media, to be honest, but if you want to, you'll find all of my accounts linked there on that website. And also feel free to visit *Undark* magazine where I currently am editor-in-chief. It's a great science publication. We're based at MIT, and I like to think we do a lot of stuff that a lot of other publications miss.



Paula K. Dumas (33:07): It is fascinating. So I checked it out myself. So thank you for mentioning that. Well, Tom Zeller, thank you for joining us today at the Migraine World Summit.

Tom Zeller Jr (33:16): It's been terrific. Thank you for having me.