

Mayo Clinic Podcast - Dr. Jeremy Cutsforth-Gregory - 05 16 2...

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SPEAKERS

Dr. Jeremy Cutsforth-Gregory, Dr. Halena Gazelka, Narrator

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- N** Narrator 00:00
Coming up on Mayo Clinic Q&A,
 - D** Dr. Jeremy Cutsforth-Gregory 00:03
About 85% of patients will have an orthostatic headache, one that gets worse as they stand up, better when they lie down. But even those patients and then the rest of the patients have other things like dizziness, ringing in the ears, sometimes double vision or changes in vision. There's even a type of dementia that can be caused by when the brain sags down somewhat.
 - N** Narrator 00:21
These conditions are often caused by membranes surrounding the brain or the spinal cord leaking cerebral spinal fluid. This fluid provides cushioning, and if the leak is not treated, it can cause long-lasting harm to the brain or the spinal cord.
 - D** Dr. Jeremy Cutsforth-Gregory 00:35
It's debilitating. It can go on for years. We're doing our best to educate both patients and

providers on how to recognize it, because whether that means someone can get treatment locally or be referred here, and we want to help because this is usually a treatable, reversible condition.

D Dr. Halena Gazelka 00:50

Welcome, everyone to Mayo Clinic Q&A. I'm Dr. Halena Gazelka. Cerebrospinal fluid, or CSF, is the clear fluid that surrounds the brain and spinal cord. CSF cushions the brain and spinal cord from injury, delivers nutrients, and acts as a waste removal system for the brain. A CSF leak occurs when fluid escapes through a small tear or hole in the outermost layer of tissue that surrounds the brain or the spinal cord. CSF leaks can occur in the brain or at any point along the spinal column. So, how are CSF leaks diagnosed and treated? Well, believe it or not here at Mayo Clinic, we have scientists and physicians who are experts exactly in that topic. Joining us to discuss this today is Mayo Clinic neurologist, Dr. Jeremy Cutsforth-Gregory. Thanks for being here today, Jeremy.

D Dr. Jeremy Cutsforth-Gregory 01:42

Thanks, Halena. It's great to be here. I really appreciate it.

D Dr. Halena Gazelka 01:45

Well, I like to learn something new every day, as our listeners know, and I have to say that this is one of those topics that I don't think that a lot of people probably know a lot about.

D Dr. Jeremy Cutsforth-Gregory 01:55

That's right. I mean, we'll talk about a couple different types of CSF leaks today. But all of them I think are under recognized. And it's important to recognize them because we can treat them, as you know,

D Dr. Halena Gazelka 02:04

it's interesting, because you see a lot of patients with this issue.

D Dr. Jeremy Cutsforth-Gregory 02:08

I do yeah, part of it is the referral bias, right. There's aren't too many centers in the country that are really expert in these spinal CSF leaks, but we're one of them. And so, I get to see these patients almost every day.

D Dr. Halena Gazelka 02:17
So how common are CSF leaks?

D Dr. Jeremy Cutsforth-Gregory 02:21
The data are not the strongest, but they would say perhaps five per 100,000 people, but that's a gross minimum, I think I've got to be seeing more than that. And I think if we were to do an epidemiologic study, we'd see the number is at least double that.

D Dr. Halena Gazelka 02:34
Wow, I was going to say, I feel like you see many more patients than that quite frequently. But that's interesting. Can you tell us a little bit about the difference between leaks that occur around the brain or skull base and spinal cord? Do they have differences?

D Dr. Jeremy Cutsforth-Gregory 02:51
For sure, and I think that's probably the most important kind of breakdown that we make right off the bat, which is leaks that come either out the nose or out the ear, what we call the skull base leaks, and leaks that occur along the spine. Because the symptoms are different, the treatments are different. So first with skull base leaks, that's usually in patients if they don't have trauma or neurosurgery. So, we're talking about spontaneous issues here, it's patients with high pressure inside the head. And that can happen in young women who are overweight would be the most common. And that's not the same for spinal leaks. That can be almost anyone, and the symptoms of a high-pressure headache, worse at night, you wake up with a headache in the morning and you get leakage you can lean forward, and drip, drip, drip, out it comes.

D Dr. Halena Gazelka 03:30
Interesting.

D Dr. Jeremy Cutsforth-Gregory 03:31
The spinal leak patients, they stand up and they get a headache. So, you know, in your practice, you treat a lot of patients who get spinal taps who have the aftermath of a spinal tap. It's similar, they stand up they have a headache, they lay down they usually feel a bit better. There's a whole wide range of other symptoms, but that's the most common one. And that's from a spinal leak, not from a skull-based leak.

D Dr. Halena Gazelka 03:49
Okay. So, is that the only symptom or side-effect that someone might experience if they were having a CSF leak and would come to medical attention is the headaches?

D Dr. Jeremy Cutsforth-Gregory 04:01
No, it's not. That's probably why it's not recognized very often. About 85% of patients will have an orthostatic headache, one that gets worse and they stand up, better when they lie down. But even those patients and then the rest of the patients have other things like dizziness, ringing in the ears, sometimes double-vision or changes in vision. There's even a type of dementia, that can be caused by when the brain sags down so much, which I'm sure we'll talk about later, that it puts pressure on certain regions and can cause a frontotemporal dementia. So, it's a wide range of things, and I think that's probably why the diagnosis doesn't always come to people's mind.

D Dr. Halena Gazelka 04:33
Are there certain risk factors that would lend itself to someone developing this?

D Dr. Jeremy Cutsforth-Gregory 04:39
Yeah, the most common risk factor for the spinal CSF leak is joint hypermobility. So maybe this patient actually has connective tissue disease like Marfans, or Ehlers-Danlos, but often they just have a degree of kind of double jointedness. So, I'll ask patients about that, including, you know, can you bend your elbows backwards or can you touch your fingers if you reach over, above and below behind your back. Or have you ever dislocated a shoulder or hip, they pop out of joint. Because that can be a risk factor that maybe their connective tissues are looser or more prone to leaking. And we probably should put a name to that, too. So, we talked about the lining that of the brain and the spinal cord, and it's called the meninges, it has different layers. The outermost layer is called the dura. So, sometimes people will have a tear of the dura or a tear in the meninges, or inflammation called meningitis. The terms get a little bit messy, but it's that outer layer, just like you said at the start.

D Dr. Halena Gazelka 05:27
Interesting. How do you diagnose a CSF leak?

D

Dr. Jeremy Cutsforth-Gregory 05:30

It starts with the story, right? So, asking patients if they come to me with headaches, is the most common symptom. How did it start? Did it come on all of a sudden? Which is what you might expect for someone who suddenly developed a tear and a leak? Or was it something that you had a couple days a week, and then every day and then now around the clock? Is it worse, when you're upright? It's important to know sometimes people start out with a headache that's worse when they're upright. But over time, it just develops a headache around the clock. So, we don't ask them about how the headache was at the start and won't be thinking about it. Once I have a clinical suspicion, then I go for imaging. The first test really is MRI scan of the brain, because it'll show changes, either the brain sagging down from where it belongs, or that meninges, the outer layer, getting thicker and taking up the contrast dye more than normal.

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Dr. Halena Gazelka 06:14

Interesting. So, are there different types of CSF leaks that happen in the spinal column?

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Dr. Jeremy Cutsforth-Gregory 06:21

Yeah, they're now recognized as kind of three big types. So, the first one would be a bone spur that cuts through the dura, or the meninges, and causes a leak. And I think that's probably the easiest to visualize or conceptualize. Those tend to be what we call fast leaks. It doesn't mean the symptoms are worse, it's just the flow of fluid leaking out, is actually faster and builds up pockets that we can see on an MRI scan. The next most common is something that would be where the nerve exits the spinal cord, it has to exit out through the dura, I think of it kind of like a sleeve, right, there's a little bit of lining that holds all the fluid in. Well, sometimes in the armpit or around that sleeve somewhere it gets a tear, that's a type two leak, is a tear in the nerve root sleeve, then the most recent, and this is the one where we've made a lot of advances recently, is called a fistula. So, you know, a fistula is, you know, is two tubes that connect that aren't supposed to. Well, if the nerve root sleeve connects to a vein, it lets the spinal fluid escape. But it's not just going out into the soft tissues, its actually into the bloodstream and washing away like a little siphon. And the very first fistula was described in 2014. That doesn't mean they didn't exist until them, but we didn't even know they existed until that. And so, just in the last seven years, we've made big progress in figuring out how to find a fistula. Sometimes some clinical features that make us more suspicious of the fistula type versus the other ones, and then a new treatment too. And I hope you'll ask about that, because I'd love to talk about the treatments of fistulas.

D Dr. Halena Gazelka 07:39
Well, what a wonderful opener for me. Jeremy, tell me about the treatment for CSF leaks.

D Dr. Jeremy Cutsforth-Gregory 07:45
Yeah, so the type one and type two, I get to rely on you and your colleagues doing blood patches. So, it's putting a needle in near the spinal sac, near the dura, and injecting the patient's own blood to try to kind of clot it off. Cover the hole, let it form a scar that works for the type one sometimes, definitely works with the type two leaks, but the fistula, that blood actually can't get into that internal hole. And so, for that we'll do a catheter through the groin, snake it up into the spine, and then glue the vein shot from inside. It's a minimally invasive and very effective treatment, that in the past, we would have had to have done a spine surgery to cut open the spine and correct. But now we can do it through a catheter-based process. Mayo is a fantastic place to get to make those kinds of advances.

D Dr. Halena Gazelka 08:26
Yes, because you do see so many patients who have this issue that allows even those who treat it to be more helpful to you.

D Dr. Jeremy Cutsforth-Gregory 08:35
Yes,

D Dr. Halena Gazelka 08:36
And have experience. Are there any expected side-effects or complications from the treatments that are delivered?

D Dr. Jeremy Cutsforth-Gregory 08:42
Yeah, the most common one is actually when the treatment works too well, by which I mean you plug the hole, but the patient has been living in that kind of low-pressure state. And so, the body compensates by overproducing spinal fluid. So, then when you correct it, they go into a rebound high-pressure state for a period of time. It's usually pretty mild, usually doesn't last more than a few days or maybe a couple of weeks. But there are occasional patients who we need to put temporarily on a medication to reduce spinal fluid production until they kind of equilibrate back to a normal level. You'll call that

rebound intracranial hypertension. But it's really a good sign, it means the treatment worked.

D Dr. Halena Gazelka 09:15
How often do you have to repeat the treatment?

D Dr. Jeremy Cutsforth-Gregory 09:19
So, if we do a blood patch, it really depends if the patch is at the site of the leak. So, the treatment is important, but finding where to apply the treatment is actually the most important step. And if we know where the patient's leak is, one or two blood patches, usually it's pretty effective. And if not, then we would consider a surgery. If we don't know where the leak is, and we're doing blood patches, you know, kind of just wherever it's safe, or maybe at a couple of good guesses, often we do a series of blood patches every couple few months for those patients. So, it really depends, and when the treatment isn't working, to me, the takeaway is we haven't found the leak. We need to go looking for the leak again.

D Dr. Halena Gazelka 09:53
That's interesting. I think one of the things that strikes me the most about these patients when I have the opportunity to assist you and caring for them, is the incredible struggle that they go through getting to a diagnosis. So sometimes, you know, you can explain this better than I can, but there's patients who have probably years of treatment, or management for other types of headaches or other presumed issues before they get to this diagnosis.

D Dr. Jeremy Cutsforth-Gregory 10:19
Yeah, unfortunately, that's exactly true. Patients who have had at least months if not years of headaches that have been called migraines, you know, they might even have some features of migraines, but they never respond to migraine drugs. So, patients are put through months and months of medication trials. And to me really the key feature is if you're lying down and feeling better, it's probably not a migraine. A migraine has to get better with sleep, not just lying flat. If they have the dementia, if someone isn't aware that this is one of the rare causes of dementia mimic, it can be treated with dementia for years, and I just saw a patient like that recently. She's having one of those embolization, the glue it shut procedures next week, and really looking forward to seeing her get better. It's debilitating. It can go on for years. We're doing our best to educate both patients and

providers on how to recognize it. Because whether that means someone can get treatment locally or be referred here, we want to help because this is usually a treatable reversible condition.

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Dr. Halena Gazelka 11:12

And what is amazing to me is that it seems that with whichever treatments they qualify for, based on their leak that often the response is pretty quick, you know whether it worked fairly soon. Yeah, a lot of people, you know, the same day, sometimes even on the table, like I'm not the one doing the blood patch, but I'll ask them, when did you start to feel better? And it's probably when they're with you, right? They say, oh, my hearing cleared up right away, or my headache started to get better right on the table. And it's gratifying for me. And I'm not the one in the moment. So, I imagine it's fun for you too. Yeah, it's often when they sit up or get up to walk out, they're feeling much better, that is really gratifying. Jeremy, are there any medical therapies that you use to treat CSF leaks?

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Dr. Jeremy Cutsforth-Gregory 11:54

There really, sadly, there are not medications that are going to help these headaches much. Occasionally we'll do a short burst of steroids to try to kind of buy just a little bit of time to get the workup completed. But for the most part, it's a matter of expediting the workup to find the leak and give a blood patch. I mentioned a medication to temporarily lower pressure after treatment. So, that's probably about the only time I end up using pills.

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Dr. Halena Gazelka 12:16

That's interesting, because I can imagine that you probably then see patients who've been through a lot of different medical therapies before they make it to you to have an actual diagnosis.

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Dr. Jeremy Cutsforth-Gregory 12:25

Yeah, that's right. And so, one of the things I'm often doing is taking things off their medication list, and outlining ways to titrate off these medications.

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Dr. Halena Gazelka 12:33

Sure. Anything else you'd like to share with us today about CSF leaks? No, I really just highlight that what it takes is a multidisciplinary team. And I think that's why Mayo Clinic is able to do this. So, I'm a neurologist, and maybe kind of the frontline assessing these

patients, but I couldn't do it without anesthesiologists to do the blood patches, radiologists to do and interpret the scans that are sometimes quite subtle, and occasionally a surgeon to fix when we can't do it other ways. So, it's a multidisciplinary effort. It's a great privilege to be part of that team, and here's the place we can do it well. Jeremy, we've been talking that during COVID, we've increased the use of telemedicine or virtual visits for some of our clinical areas. Do the patients that you see benefit from virtual visits, either before they see you or afterward, or is that not something that you can do a virtual visit for?

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Dr. Jeremy Cutsforth-Gregory 13:23

We've done it both ways. And there are certainly times where it works. So, that initial evaluation, you know, I can get a story by telehealth quite well and save the patient the trip and kind of outline, okay, so which tests are we likely going to need and get them pre-scheduled. So, we've done a fair bit of that. And then after a blood patch, or after any sort of treatment, we've now put in place a video visit with our nurse who is quite experienced with this, kind of at the one-month mark. So, the patients know there's going to be a time to give a status update. It's offloaded the clinical schedule just a little bit, so we keep seeing new patients, and then we know at the one-month mark, do we need to do another treatment, more testing, or is the patient doing well? So, we're using telehealth for sure. Now they have to come here to get the high-quality imaging and to get the treatments, but if we can, you know, start adding telehealth I think it's saving a lot of people some time and convenience.

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Dr. Halena Gazelka 14:08

And a real confidence booster for patients knowing that when they go home, they can still have continuity of care with us.

D

Dr. Jeremy Cutsforth-Gregory 14:14

Yes, it's definitely been a nice way to stay connected.

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Dr. Halena Gazelka 14:17

Well, thanks for being here today, Jeremy.

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Dr. Jeremy Cutsforth-Gregory 14:19

Thank you Halena very much.



Dr. Halena Gazelka 14:22

Our thanks to Mayo Clinic neurologist, Dr. Jeremy Cutsforth-Gregory for being here today to discuss cerebral spinal fluid leaks, how they are diagnosed, and how they are managed. I hope that you learned something, I know that I did. And we wish each of you a very wonderful day.



Narrator 14:38

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