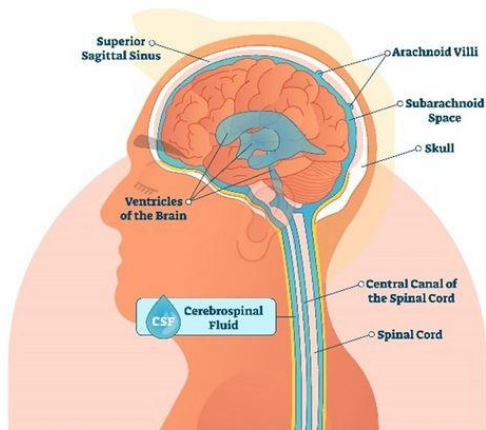


About Intracranial Hypertension

CEREBROSPINAL FLUID



About IH

Each time we enter a doctor's office, our arms are cuffed, and blood pressure checked. It's common knowledge that high blood pressure or low can cause a variety of symptoms. And yet, a large portion of the medical community (and likely an even larger portion of the general public) pays no heed to cerebrospinal fluid pressure. Whether you have a severe chronic illness, are mostly functional, have an injury, or no illness at all, please take a moment to learn about

intracranial pressure and how it may be affecting you, along with millions of others, often without our awareness.

The skull contains a closed system of brain, blood, and cerebrospinal fluid. To maintain intracranial pressure (ICP), a delicate balance must be preserved.

Cerebrospinal fluid surrounds the brain and spinal cord, providing protection, nourishment, and waste removal. When something goes wrong—with, for instance, the mechanism that absorbs or drains CSF, the “supply lines” into the skull, illness, or injury—pressure can increase inside the skull, and bone is unable to accommodate expansion. **This is high pressure—intracranial hypertension.**

The pressure and volume relationship between cerebrospinal fluid (CSF), the brain, and the vascular system must be maintained. High intracranial pressure can injure your brain or spinal cord, limit blood flow to the brain, or cause a myriad of symptoms. Low intracranial pressure can cause an even larger variety. *(To learn about intracranial hypotension and spinal CSF leaks, [click here.](#))*

Intracranial hypertension in adults is defined as intracranial pressure of 250mmH₂O or above. But an opening pressure on a lumbar puncture may not

always be a useful guide, as recent findings reveal that pressure can fluctuate. Positional changes, medication, or duration between spinal taps could also affect results. **A normal opening pressure does not rule out intracranial pressure issues.**

Because CSF pressure fluctuates, symptoms can fluctuate as well.

Acute IH can have a rapid, identifiable onset as the result of head injury/brain swelling or intracranial bleeding (aneurysm or a stroke) into the sub-arachnoid space surrounding the brain. In these cases, parts of the skull may be removed to accommodate the additional pressure.

Chronic IH is a neurological disorder in which CSF pressure remains elevated over a sustained period of time. Causes can include injury, illness, medication, stenosis, and much, much more. If the cause is unknown, it may be referenced as idiopathic intracranial hypertension (IIH) or if secondary to another cause, secondary intracranial hypertension (SIH). It was previously known as pseudotumor cerebri because it mimicked the symptoms of brain tumor, but this term is out of use.

IH can be a lifelong condition, and may be mild, intermittent, or disabling.

(Dive further into cerebrospinal fluid mechanics [here](#) or check out the [research](#) page for more.

Symptoms

Symptoms will vary. Not every person will have headache, or vision issues, or any of the less common side effects of high pressure. Assumptions otherwise is the reason many cases are misdiagnosed.

Key Symptoms

- Headache, head pressure, or head pain, as with low pressure, is a key symptom of IH. Intracranial pressure headaches may not be relieved pain medication. IH headache may share migraine characteristics, such as light and scent sensitivity, and worsening with exertion, cough, or straining. Migraine, however, should not be accompanied by pulse synchronous tinnitus, or the visual issues excluding aura (temporary flashing or flickering objects, usually lasting about 20 minutes prior to

migraine onset, and disappearing after head pain begins). IH headache may not occur in one specific area. Pain may be located behind eyes, forehead, one side of head, back of head, base of skull, top of head, or may be burning or pressure type pain, and may be made worse by eye movement. Not everyone with IH has all head pain symptoms.

- Vision—IH can cause rapid or progressive vision changes. Vision symptoms may include gray spots, dots, floaters, or dim-outs in one or both eyes, blurred vision, or double vision. Papilledema caused by CSF pressure on the optic nerve and blood supply can lead to vision loss. Not everyone with IH has all vision symptoms.
- Pulse-synchronous tinnitus (whooshing, whistling, humming or marching noises in one or both ears that correlates with your heartbeat)

Other Symptoms

- Fatigue or sleepiness
- Lack of alertness, brain fog, memory or other cognitive issues
- Mood issues including depression, anxiety, irritability, and more, or behavioral changes
- Weakness, issues with movement or speech
- Nerve pain in the neck, shoulders, arms, upper or lower back, hips, legs, or feet
- Neck or shoulder stiffness
- Dizziness, lightheadedness, balance problems
- Numbness or tingling in hands, feet, or face
- Nausea or vomiting
- Clear fluid leaking from the nose (many assume this is only allergies)
- Endocrine issues (due to empty sella syndrome and the flattening of the pituitary gland)
- Malaise
- Exercise intolerance

These symptoms may appear in a variety of patient groups, yet many do not realize they may be attributed to ICP. It's important to remember diagnoses considered rare can be disregarded *because they are considered rare*.

It is known that the longer a leak (low ICP) goes untreated, the less pronounced the orthostatic changes can become. Less clear is whether this also happens with high pressure cases, but it's worth noting the signs may be clear at onset but more difficult to untangle over time.

A Connection to Chronic Pain and Fatiguing Illnesses

It's hard to ignore the parallels between ICP and other illnesses. The spinal CSF leak page gives insight as to how low intracranial pressure can mirror the symptom set of ME/CFS right down to PEM, and that some symptoms may only be relieved by pacing and rest (because getting flat allows the CSF to resume its place the brain). With high intracranial pressure, the increased pressure can force cerebrospinal fluid into nerve root sheaths, causing severe nerve pain that can be relieved somewhat by gentle upright activity, as in fibromyalgia.

If nothing else, these similarities could be causing misdiagnosis, and intracranial pressure should be considered as part of standard testing. ICP is also considered a factor in Long Covid, and no one can deny the similarities between it and ME/CFS.

What's more, high intracranial pressure can be brought on by illness.

A few additional causes of increased intracranial pressure include:

- Underlying illness, such as Meningitis, Lyme disease, Coxsackie B viral encephalitis, Guillain-Barre syndrome, Infectious mononucleosis, Lupus, Sarcoidosis, Hypoparathyroidism, Addison's disease, Behcet's disease
- Medications (this is an extensive list, but some major actors are the cyclines—doxycycline, tetracycline, minocycline—or Accutane, Retin A and topical products and face creams, prednisone which may cause temporarily improved and then severely worsening symptoms, estrogen, and more—Google the medicine with “cranial pressure” to check)
- Vitamin A
- Cerebral blood clots (cerebral venous thrombosis)
- Infection
- High blood pressure
- Tumor
- Stroke

CSF pressure issues may also be aggravated by flow problems such as stenosis, drainage issues, or many things mechanical, and made worse by lax dura mater related to connective tissue disorders.

The Question of Position

As with spinal CSF leaks, the mantra of positional symptoms applies (but here, in reverse).

Pressure issues may not be part of standard testing but simple at home observation can sometimes give major insight.

1. *Decide on standing straight or lying completely flat (spine straight, no pillow). **Focus on your symptoms.** Write them down if you need to—especially given cognitive issues can be a big symptom. (If you're bedbound, read about [spinal CSF leaks](#) first.) Think about the entire package: scan the pain in each area of your body. Don't leave any parts out. Feet, neck, back, stomach, but especially pay attention to what's happening in the area of your neck and skull. Think about your mood and the general feeling of wrongness or offness you may find. If you're flat, do you start to suddenly have anxiety? Do your legs become restless or move of their own accord? Do you feel tingling or burning at the top of your skull or ears? Does your vision change? Can you read a spot of text at a distance with the same clarity as before? Are your ears ringing more? Can you feel your pulse in your ears? Is your heart racing?*
2. *Change position, opposite of what you were. If you were standing, get flat. If you were flat, gently walk through the room. **Focus on your symptoms.** Do you find relief—even minor—of any of the symptoms you noted before? If you stay in those positions longer, hours or more, does it change your response? If you're uncertain, watch it for a week. Do you only find yourself weeping uncontrollably after you've done a physically demanding project? Do you feel worse after activities where you're eating restaurant food or indulging in high sodium meals? Write it down, track it over time, and notice every change in relation to your position, activity, and food.*

What does this experiment tell us?

→ If you feel better when you lay down and stay down, look into hypotension and leaks.

→ If you feel worse when you're flat, look into intracranial hypertension (high pressure).

Things to Consider When Seeking Diagnosis

To diagnose IH, your doctor may start with a general exam or neurological exam, followed by imaging such as MRI and CT.

MRI findings may include flattening of the pituitary gland, which gives the appearance of an empty sella turcica. In addition, the sclera (white outer layer of the eye) at the back of the eye can appear flattened. High pressure may be hereditary, depending on the underlying cause. Imaging may only be one of many tools your doctors use to determine your underlying cause.

Did you already have a lumbar puncture and felt relief? This may indicate high intracranial pressure. If you did not eventually resume your baseline afterward, or felt substantially worse over the following days or months, this may indicate low pressure due to a leak, or you may already have been leaking. (If so, check out the spinal CSF leak page.)

Chiari and Brain Sag—Congenital, leak, or downward pressure?

According to studies, over time IH may cause an acquired Chiari malformation. Acquired Chiari (or brain sag) may also be the result of low fluid, such as CSF leaks, or LP shunts or multiple spinal taps. Per the IHR Foundation, research suggests acquired Chiari malformation is eight times more common in chronic IH patients who have not had shunting procedures.

Find out more at: <https://ihrfoundation.org/what-is-ih/ih-and-related-disorders>

*As with leaks, it is essential to find a specialist experienced in pressure issues and armed with the most current information. **Don't let the incorrect notion that pressure issues are rare prevent you from finding treatment.** If you fit the profile and your physician dismisses the possibility, consider a second opinion with an experienced specialist.*

The official ICP diagnosis criteria can be found here <https://ihrfoundation.org/what-is-ih/diagnosis>

Treatment

To treat IH, intracranial pressure must be lowered. Like leaks, this can often be done in a relatively easy manner. Carbonic anhydrase inhibitors can reduce spinal fluid, including Diamox (acetazolamide) and the less potent Lasix (furosemide), Topamax (topiramate), and Neptazane (methazolamide).

It is important to understand that while lumbar punctures, or spinal taps, may temporarily ease IH symptoms, spinal fluid regenerates at a rate of .3cc per minute. The body produces, absorbs, and replenishes the total CSF volume several times each day. And, as many well know, lumbar punctures carry the risk of creating a CSF leak that may worsen a person's condition considerably. Neurosurgical shunts are an option in certain cases but also carry more risk.

Tips for coping with IH in addition to or outside of medical intervention

- Consider reducing sodium to the minimum daily recommendation, then raise it as you're able (some may have a much higher tolerance). Be diligent, as sodium is in nearly everything. Check your condiments and spices and read labels and serving sizes on packaged food. *(Please consult your physician before making drastic diet changes.)*
- Avoid straining, heavy lifting, pulling, etc. Gentle upright activity only. Walking is encouraged.
- Don't bend over if you can help it and avoid sitting in one spot for long periods (if you're more functional, you may have noticed issues while driving or at events with rigid seating).
- Sleep on an incline, head elevated and neck not kinked to prevent flow. (Wedge pillows are excellent helpers.)
- Some people avoid vitamin A foods. Others do well with diuretic foods.
- Watch for barometric changes or hot temps (including hot showers).
- Avoid certain medicines like steroids, cycline antibiotics, and Retin A.
- Some people are affected by sugar or caffeine. (Caffeine affects blood flow in the brain and may affect CSF production.)
- Avoid postures that crimp the neck (as when looking at your phone or tablet).
- Avoid tight clothing or abdominal binders.
- Watch for your own triggers, be it food, weather, elevation, or certain positions.
- Know that it may change by factors out of your control.

Resources

Questions to consider as, no matter one's condition, pressure may affect them in ways they may not have realized. Even the relatively healthy can be affected by pressure changes and these may help you notice when and how your symptoms occur.

- *Do you feel worse—either immediately or within days –after strenuous activity such as lifting, high stress events, after sneezing/coughing, or bending or twisting? This may indicate a leak or high pressure, or a cycling between the two.*
- *Have you had an unusual (good or bad) reaction to doxycycline, prednisone, or any medicine that affects cranial pressure? Does caffeine, salt/processed foods, or B1 affect the severity of your symptoms? (Google the medicine or food with “cranial pressure” to find connections)*
- *Do you feel worse in the evenings or have vision or head or neck pain changes as the day progresses? Do you feel worse at different elevations or with barometric pressure swings?*
- *Do you find your mood shifts with your symptoms after these activities? Are your cognitive or neurological symptoms brought on by bending, lifting, twisting, jumping, straining, or Valsalva maneuver? Is some part of your pain positional?*
- *Do you have unusual scarring, stretchy skin, or have joint hypermobility in your family? These may be signs of a connective tissue disorder, making leaks and pressure issues more likely.*
- *Do you ever feel anxious or restless when lying down? This may be high pressure urging you to get upright (to ease pressure in the skull). Do you ever find relief by lying flat? This may be low pressure returning needed fluid to your brain.*

Think about how these factors affect your symptoms. If you believe you have a spinal CSF leak or IH, discuss it with your care team.

Useful links:

Intracranial Hypertension Research Foundation (information on IH) <https://ihrfoundation.org/what-is-ih>

Spinal CSF Leak Foundation Physician Directory (doctors experienced in intracranial pressure issues) <https://spinalcsfleak.org/directory/>