IP Survey IP1996

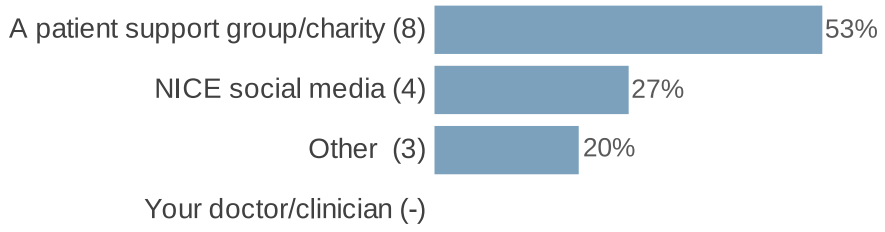
This report was generated on 22/08/25. Overall 15 respondents completed this questionnaire. The report has been filtered to show the responses for 'All Respondents'. A total of 15 cases fall into this category.

The following charts are restricted to the top 12 codes. Lists are restricted to the most recent 100 rows.

I have read the information above which explains the purpose of the project and how any information I provide will be used

I consent (agree) to NICE using the information I have given in the ways described above

How did you hear about this survey?



If other, please specify

LinkedIn
LinkedIn: CSF Leak Association
Facebook group

Are you (the person completing the questionniare)

Your age

57	47	57	58	54
53	39	62	36	41
60	24	47	78	54

In years

11/2	2
1	1
2023	3
1	1

In months

4	8	28	5
Match	9	6	8
5	11	6	7
9			

in weeks

0
2
2

To which gender identity do you most identify?

What other treatment options did you consider, and why did you choose this one?

Three bloodpacht was not working

None because I previous had great results from this procedure

I was only offered this treatment

9 blood patches, surgery. We chose the embolization as a less invasive treatment option once the leak locations were found

I considered epidural blood patches but those are almost never effective for CSF-venous fistulas.

Only other option was blood patching and I wanted to start with something with a higher success rate.

This was the only option

2 prior surgeries failed. Then 3 embos

Fibrin glue injection first (04/30/2024), my second option after it was the embolization (9/6/2024)

I could have sought open spinal surgery to close my CSF venous fistulas (CVFs), but I much prefer the less invasive option with transvenous embolization (TVE), especially since I've had three CVFs found and closed so far. I'd MUCH rather have multiple TVEs than multiple open spinal surgeries.

Before my embolization, I had 3 unsuccessful blind blood patches and a patch with cyanoacrylate glue. The blood patches lasted 0-6 weeks, while the glue patch lasted about 10 weeks until my symptoms returned.

No other options

I considered a laminectomy, but chose the embolization thinking that the recovery period would be easier.

I have a csf venous fistula

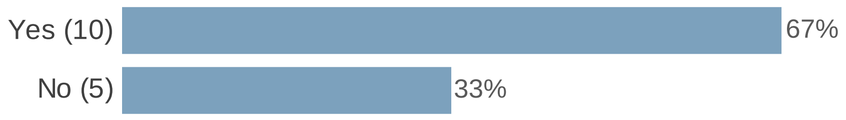
None. Least invasive and had worked for me before

Did the procedure work?

If **somewhat or no**, please provide further details along with information about whether symptoms later reoccurred.

for a year it works but I have two new leaks
If worked for about 6 months before ultimately failing
I’m dealing with extreme pain and pulsating at that spot since embolization (so unsure if fully sealed), and also have opened up new fistulas in different spots since then.
I still had a leak from the vein. I had a blood patch done 4 months after the embolization.
1 was March 2024. Partial help to csf cervical leak. Caused Horners syndrome. 2 was July 2024. Decreased function brachial plexopathy. 3 was December 2024. Caused parsonage turner syndrome and further function lost. All fine with onyx. Not sealed yet. Too much onyx to image or try surgery. Tried epidural for pain relief but can’t see the area.
Unfortunately I continue with headaches and my last MRI (March 2025) showed that I’m still with intracranial hypertension
I mean, yes, all three TVEs successfully closed the three CVFs that were identified in my imaging, but none of the TVEs have brought me relief, likely because I still have another leak somewhere, as suggested by my follow-up brain MRI, which still shows a sign of SIH (worse effacement of pre-pontine cistern), and two PCCTs still show early renal contrast. (I also have a history of smooth, diffuse dural enhancement extending from ear to ear, into both internal auditory canals, but that disappeared in my fourth year of illness.)
During the embolization, they punctured the vein near my heart before reaching the embolization site. The surgeon immediately aborted the surgery.
Only 1 level.done. no change in my symptoms

Did you have any side-effects following your procedure?



If **yes**, please provide further details along with information about whether symptoms later reoccurred.

I had a lot of intracranial hypertension and diamox caused me metabolic and respiratory acidosis

High intracranial pressure for many months after

extreme RHP with papilledema plus pain and swelling at the groin access sites

I had this procedure done four times for a total of ten fistulas. I had rebound high pressure after all of them and had to start Diamox (acetazolamide) the morning of the procedures to prevent my pressure from going too high and causing new leaks to form. Seven of my fistulas were located in the internal epidural venous plexus and the recovery from those embolizations was incredibly painful for a period of week to months. Unfortunately, due to my underlying connective tissue disorder, I always opened new fistulas at different locations after each embolization.

Pain and pulsating, also still have all leak symptoms due to new fistulas or possible recurring fistula at embolization site

High pressure headache for a few days after.

Previous page. Horners syndrome, brachial plexopathy structural compression then later superimposed parsonage turner syndrome. Now, sarcoidosis. Related? Probably not?

Never pain in my arm and leg

I had mild pain in my back for maybe 2–3 days and moderate sciatic pain that slowly went away within 2–3 weeks. This was a much easier recovery than my three high volume, multilevel, non-targeted Epidural Blood Patches, EBPs, and a comparable recovery to my six low volume, targeted fibrin+blood patches (though none of those worked).

I had rebound high pressure for 8 months, until I had an LP to remove excess fluid.

How long did it take you to recover from the procedure?

One year

9 months

It was instant. My operation was 5 & half hours. Once I had come round I was immediately better. Every symptom had gone.

3 mo

Typically a few weeks.

Unsure how to answer, pain has worsened since then

Once the high pressure headaches subsided I was good for a few weeks and then my leak headache returned.

Haven’t.

1 month

The back pain lasted a few days and the sciatic pain lasted 2–3 weeks.

I was able to get back on my feet within 3 days of the procedure. I did develop rebound intracranial hypertension (without papilledema) in the weeks following the procedure, but I was able to manage those symptoms with methazolamide or acetezolamide. My understanding is that there is a subset of people who develop these symptoms whether they have a blood patch, surgery, or embolization. Otherwise, the procedure was completely painless and I didn't experience any side effects.

About two months

I was hospitalized for 3 nights following the procedure to ensure healing of the punctured vein and no complications to heart and lungs.

1 day

The procedure itself only took a few days but subsequent high pressure was tough to manage.

How did the procedure positively affect your condition and/or your quality of life? Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

despite the hypertension I regained my life, my cognitive functions and started all my activities again!

No more headaches or balance problems. I can now work full-time without needing to lay down 5 times through the workday. This illness impacts your entire family and causes great emotional stress for the entire family. Now, we can all lead a normal life!!

My leak was from September 2021 up until my operation in March 2023. My symptoms over that time period gradually got worse. The headaches were severe, I basically had dementia, shouting, repeating myself, no ability to retain even the simplest instructions/words, choking on food. My operation just gave me my life back, my husband his wife back & the adult kids their mum back. I celebrate the date of my operation every year & will do till I die. That’s how significant it was.

I was able to be upright but the RHP was difficult to manage

For the times when I was sealed after embolizations, my head pain decreased, my tinnitus went away, and the fluid dripping from my nose (not CSF) stopped. I was able to be upright a bit my throughout the day. The longest I was sealed was two and a half months and during that time I had a significant reduction in pain, I was able to do more, I could interact with my daughter more, and I was so happy that I was able to participate more in life.

No positive effects

I didn’t have headaches for about four weeks and it was a huge change from having daily headaches for eight years.

Slightly made csf symptoms different but negatively affect all areas of life - pts was the negative part.

I’m still with intracranial hypotension but now I can laugh without feeling a strong headache in the back of my head like before the procedure. And sometimes (specially in the morning) I can bending over without feeling a strong headache in the back of my head. So I think the procedure is very good, I recommend it because I feel better, I’ll do it again! Right now I’m positive, optimistic waiting for my appointment, for my next treatment …hopefully I get relief, hopefully they can totally to fix the leak!

Unfortunately, my three TVEs did not improve my any of my symptoms or quality of life, likely because I still have more CSF leaking from somewhere within my spine. (Follow-up brain MRI showed increased effacement of pre-pontine cistern and two PCCTs showed early renal contrast with normal OPs of 10 cm H2O.)

Within 48 hours the procedure eliminated the following symptoms: orthostatic headache, gastroparesis, severe dry skin, dry mouth, and severe light and sound sensitivity. It's taken more than a year since my repair for all of my light sensitivity and ease at which I can read to significantly improve. In terms of my mental and emotional wellbeing, I'm no longer prone to panic attacks and the extreme depression that coincides with being in physical agony while lying flat in a dark bedroom 24/7. After my repair, I've been able to meet my nephew for the first time, as he was born shortly after my CSF venous fistula was repaired and visit my mom (who lives on the other side of the country) during her cancer treatment - two things that were impossible while I had an active CSF leak. I've been able to go on short walks with my husband and dog. I've started swimming again. I am in physical therapy to rebuild strength lost to being bedbound. I'm not yet back to work, but I suspect I will be a year from now. My husband, who was my primary care taker, was able to finish his PhD and medical degree without having to take more time off. I am now able to prepare my own food and contribute to household tasks. Now that I'm able to drive, I can take myself to social events and follow-up doctor's appointments. He's now more a partner than a caretaker - a dynamic we obviously prefer! I feel grateful every day for the embolization procedure that repaired my leak and for the neurointerventional radiologist who took a chance on me.

How did the procedure positively affect your condition and/or your quality of life? Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

I suffered for 13 months knowing I had a spinal leak. I consulted over 20 health professionals who could not or would not diagnose me. My mental health suffered greatly. I was not able to do anything but stay flat in bed. I lost about 15 pounds. At 74, I was treated as a “mental case” needing counseling and pain management. As a teacher with a master’s degree and 31 years of teaching experience, I felt belittled for the information I brought to the medical table. Self diagnosis is readily available if one is diligent and has a good support system. Fortunately, my daughter and my husband were the ones who kept me going. I was essentially helpless. Their burden was great. I would have died without them. Friends just couldn’t comprehend what I was going through. My initial anger with the medical establishment gradually turned to acceptance that I would die with no medical help. Depression was deep.

No impact on quality of life since it was a failed procedure. Had a lamenectomy one month later and am nearly fully recovered.

No

I am now able to work without being in constant pain. My balance and ability to walk is perfect. I highly recommend this procedure to others with the same condition. You just need a physician to help you manage rebound high pressure after and getting a physician to help with this after can be a problem. Follow up care after the procedure is lacking and most neurologists are not familiar with rebound high pressure

How did the procedure negatively affect your condition and/or your quality of life? Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

I had intracranial hypertension and diamox caused metabolic and respiratory acidosis

I had rebound high pressure for 9 months and then had an LP to remove fluid. I have been doing well since!

It the worst thing that as ever happened to me in my life time. I lost the mental capacity to understand that I was ill, so I was still trying to live a normal life. My social life became none existent because my bed time was 5 o clock. Bending down to fill the washing machine, feed the cats was soo painful for my head. The effect on my family was immense, I was a different person. My empathy had gone. I was choking on food, repeating things in a very loud voice.

RHP made it hard to function, I could not drive or perform daily activities without headache. Mentally it was challenging as I went from RHP to leaking again.

Embolization had no negative impact on my life except for the slightly extended recovery after the embolizations that involved the internal epidural venous plexus.

Worsened pain, bedridden due to leak symptoms, unable to work/continue my education and properly care for myself

It didn’t. I would do it again if needed.

How did the procedure negatively affect your condition and/or your quality of life? Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

Already listed. Still on loa.

I can’t perform my job activities (housekeeper) I can’t lift more than 5 pounds. I can’t swim I can’t walk long distances I can’t look up (move my head up) I can’t do my daily activities in my house like before, I do some but taking a rest. Sometimes I have to miss family and friends events All this because I continue with headaches, fatigue, nauseas, dizzying

My three TVEs had no apparent lasting negative effect on my health or quality of life, unless you count the financial burden of traveling 1300 miles plus lodging.

As I mentioned in a previous, I did develop rebound intracranial hypertension after my procedure, which I needed to manage at times with methazolimide or acetezolamide. The symptoms associated with IH have been unpleasant: inability to lie completely flat, needing to manage my sodium intake, increased anxiety, risk of another CSF leak. However, they have largely subsided in the last 18 months and were nowhere near as debilitating as the CSF venous fistula/leak itself. I also understand IH to be a potential-albeit-understudied side effect of all CSF leak repairs.   The most difficult consequence of the repair was severe anxiety/PTSD around eventually developing a new fistula or leak, since I had had multiple failed procedures before the embolization. Much of that anxiety has subsided with time.

It did not negatively affect my quality of life. I felt it was a miracle. While I am deep into the aging process with connective tissue conditions, I am able to do most daily activities. I am very grateful I can spend time with my family   I still have to live with the knowledge that I could have another venous fistula again as many of us have repeat problems. My lifestyle is probably better than most people my age.

It was very challenging to have been woken up with the news of the failed surgery and that I was still leaking.

No improvement in symptoms

I had 3 embos at once and there was a lot of pain in the area of embo right after but this was only one day. The rebound high pressure headaches were a problem for months.

Did you require anymore treatment, including procedures or surgery after this procedure?

If **yes**, please provide further details.

I'm going to have an embolization again

See above

I went on to have a foraminotomy with fistula ligation at T9-10 & T10-11 at Cedars Sinai with [redacted]

I required further embolizations for new fistulas that opened at different locations.

Epidural steroid injection at embolization site and will need further leak treatment for new fistulas

Blood patch

Listed previously. 3 embos

I don’t know yet because my appointment will be soon 8/26/2025

After my three TVEs (which did not bring relief), I've had one follow-up brain MRI (showed increased effacement of pre-pontine cistern) and two DSMs/PCCTs (showed early renal contrast and suspicious areas). Now I'm trying to find a way back to either Mayo Clinic Rochester or Duke for further treatment.

One month later, I had a lamenectomy to directly seal the venous fistula at Left T10.

I received multiple level fibrin patching with immediate improvement in my symptoms although temporary

LP

Would you recommend this procedure to another patient with your condition?

If **yes**, what might you tell them?

that it has greatly improved my life

Go somewhere that has a lot of experience with this.

Because every single symptom I had disappeared & I was back to normal right away. My surgeon came over from Belfast to England to do my operation because nobody here could do it. I’m part of csf facebook groups & there’s not many successful story’s like mine. Everybody seems to have some sort of procedure & then says “I feel a bit better, still got headaches & tinnitus” So there not better are they? It’s a leak, like in a bucket, how hard is it really to stop that leak?

Skip the embolization and go for surgery if its offered! The surgery completely sealed my leak and I did not have any RHP post surgery.

Embolization is a minimally invasive procedure that can be done under general anesthesia. I would not recommend moderate sedation due to the significant pain that occurs when the Onyx is injected. It is an outpatient procedure with little recovery time required, especially compared to surgery.

This is a hard question to answer. I believe embolizations are an effective treatment, but I just personally didn’t have the best experience.

You will get your life back.

It’s the best option that with have! It’s not risky!

If **yes**, what might you tell them?

I would MUCH rather have multiple TVEs than multiple open spinal surgeries with laminectomies. I would even prefer multiple TVEs over multiple of the newer endoscopic surgeries with laminotomy as well. Plus, if I chose surgery at Cedars for my multiple CVFs and they weren't able to locate all of them, I would not want the dural reduction that's often performed there in such situations. Dural reduction may bring temporary relief, but it's unclear how lasting that is, and it might not even encompass the leak site, in which case the long-term risks of leaks and SIH would not be reduced. The only concern I have with needing multiple TVEs is how they're affecting subsequent spinal imaging, but hopefully the use of cone beam CT might help with that. Just be very sure to ask your doctor to prophylactically treat with pressure-lowering medications after a TVE, since there's increasing suspicion that rebound headache (aka Rebound Intracranial Hypertension, RIH) might be involved with causing additional CVFs.

I would tell them that if they have a CSF venous fistula, this is one of the most painless, least invasive, most durable chances they have at repairing their CSF leak. I would tell them that it's a relatively new procedure, which comes with risks, but I've met many people in support groups who have been repaired for years via embolization.

My advice would be to only to older patients. Younger people would need to get a perspective from someone their own age and support system. I had no alternative and I was willing to try anything. If one is over 65 years, I would tell them to have the embolization by a doctor who has done many of these procedures. I was lucky to get the pioneer of this embolization procedure

I was recommend the embolization but I would caution that there's a possibility of waking up still leaking.

Already mentioned-be prepared for high pressure-diamox, methazolamide. Make sure you have a physician to help with high pressure after as CSF leak centers wont manage you long term.

If the procedure had an impact on any other areas of your life that are not covered by the questions above please tell us about them here.

Do you know when an hypnotist puts someone'under' & then clicks his fingers & says “back in the room” After my operation I was Back in the room. I can not explain the happiness I was feeling. It's the greatest thing that's ever happened to me. I will always be grateful to ‘my team’

All of the additional testing and embolization was not work it. I wish I had skipped this procedure and went straight to surgical clipping of the fistulas.

Since my first of three TVEs, I've experienced spontaneous back injuries in my lumbar spine that are severe enough to prevent me from waking until aggressively treated with medications. I know that odds are good that those injuries are due to the deconditioning that comes with having SIH for eleven years (severe symptoms for nine of those years), but I've had to wonder if my back might also be affected by the nine sets of patching, nine invasive myelograms, three TVEs, and whatever effect that lie CSF volume might have on the spine.

I certainly have so much empathy for leakers. I try to encourage as many of them as I can. I also spread the word to all the medical contacts I now come into contact with. I try not to complain about the little medical issues I currently have. I have become a kinder person but more politically involved for making our medical community and nation a safer place for its citizens.