The Multidimensional Impact of Spontaneous Intracranial Hypotension (SIH)

Prof. Manjit Matharu
Headache and Facial Pain Group,
UCL Queen Square Institute of Neurology &
The National Hospital for Neurology and Neurosurgery
London, UK
&
Norwegian University of Science and Technology, Trondheim, Norway

Intracranial Hypotension Conference
Amsterdam
28 June 2025

NorHEAD
Norwegian Centre for Headache Research

Disclosure Statement

President of the Medical Advisory Board of CSF Leak Association

Chairperson of the UK Spontaneous Intracranial Hypotension (SIH) Special Interest group (SIG)

Advisory board fees: AbbVie, Eli Lilly, Lundbeck, Pfizer, Salvia, Teva Pharmaceuticals

Speaker/speakers board fees: AbbVie, Eli Lilly, Lundbeck

Consultancy fees: AbbVie, Salvia, Teva Pharmaceuticals

Grant support for research or education: Abbott, Medtronic, Ehlers-Danlos Society

Editorial board: BMC Neurology, Frontiers in Pain Research, Australian and New Zealand Journal of Psychiatry

Author royalties: UpToDate

Other: Medical Advisory Board of Trigeminal Neuralgia Association

The Human Toll of Spontaneous Intracranial Hypotension (SIH)

SIH Patient Testimony

"Being sent home by doctors to lie in a bed for months on end, with no support, no job, no life… is soul-destroying."

Why It Matters

- **Enormous Personal Toll:** Prolonged bedrest, shattered careers, strained relationships
- **High Societal Cost:** Months of sick leave, repeated ER visits, disability benefits
- **Care Gaps Persist:** Most patients endure diagnostic delays, misdiagnoses, inconsistent work-ups

Roadmap

- **Burden & Impact:** Personal, social & economic dimensions
- **Diagnostic Journey:** Common delays
- **Management Gaps:** Treatment variability & access issues
- **Outcomes & Recovery:** Quality-of-life improvements and residual challenges

1. Schievink WI. JAMA. 2006;295(19):2286–2296; 2. Mokri B. Curr Pain Headache Rep. 2001;5(4):284–291; 3. Mokri B. Curr Treat Options Neurol. 2003;5(1):43–51; 4. D'Antona R, Owler BK. Headache. 2024;64(5):1298–1308.

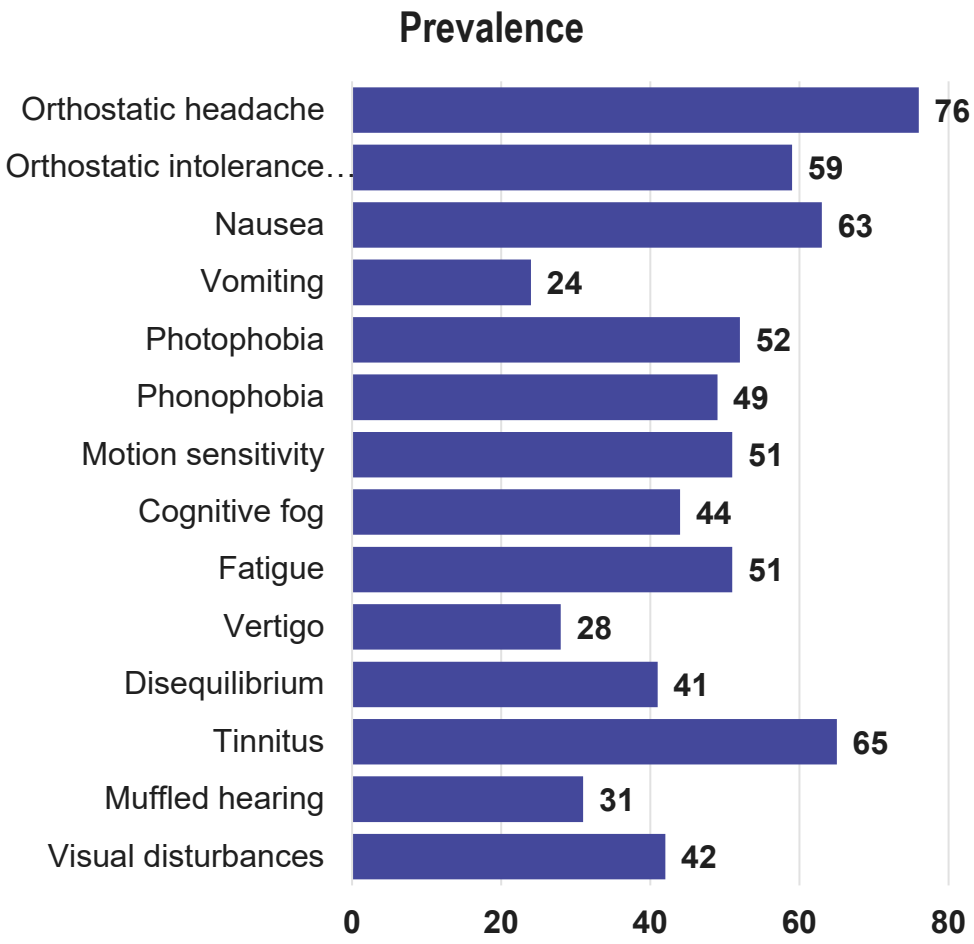
SIH Disability And QoL Studies

Author (Year)	Country (Center)	N	Study Design	Instrument(s)	Main Domains Assessed
Cheema et al. (2022)	UK (nationwide)	64	Cross-sectional online survey	EQ-5D-5L; HIT-6; HADS; custom	HRQoL; headache impact; anxiety/depression; occupational & financial burden
Jesse et al. (2022)	Switzerland (Bern)	79	Cross-sectional survey	15D; bespoke social/work questions	QoL; social & occupational impact
Amrhein et al. (2023)	USA (Duke Univ.)	15	Qualitative interviews	—	Patient-reported symptoms & functional impacts
Liaw et al. (2023)	USA (UT Southwestern)	95	Cross-sectional survey	SF-36; PHQ-9; GAD-7; FACIT-Sp-12; HIT-6; C-SSRS	General well-being; depression; anxiety; spirituality; headache impact; suicidality
Volz et al. (2023)	Germany (Freiburg)	80	Prospective cohort	HIT-6	Headache impact over time; orthostatic symptom relief
Hoydonckx et al. (2024)	Canada (nationwide)	103	Cross-sectional online survey	Custom QoL & financial questions	Physical, mental, social & economic burden; access challenges
Kapan et al. (2025)	Austria (Vienna)	86	Cross-sectional online survey	DASS-21; HDI	Depression; anxiety; stress; headache disability; work ability

Cheema S et al. BMJ Open. 2022;12:e057438; Jesse CM et al. J Neurol. 2022;269:5466–5473; Amrhein TJ et al. J Patient-Reported Outcomes. 2023;7:82; Liaw V et al. Neurology. 2023;101:e2411–e2422; Volz F et al. Cephalalgia. 2023;43(8):1–8; Hoydonckx Y et al. Can J Neurol Sci. 2024;51:650–657; Kapan A et al. Wien Klin Wochenschr. 2025;137:148–162.

Clinical Features of SIH Contributing to Disability

Structured interviews with 137 patients to characterise SIH phenotype



Mehta D et al. Cephalalgia. 2025;45(1):1–10.

Orthostatic Headache

- **Severe pain on sitting/standing forces patients to remain supine, disrupting all upright activities (work, self-care).**
- **Prevalence: 75–92 % of SIH cohorts[1,2] ; 59 % cannot stand > 4hrs without worsening symptoms[1]**
- **Impact: Median HIT-6 = 68/78 (very severe)[2]**

Audiovestibular Symptoms

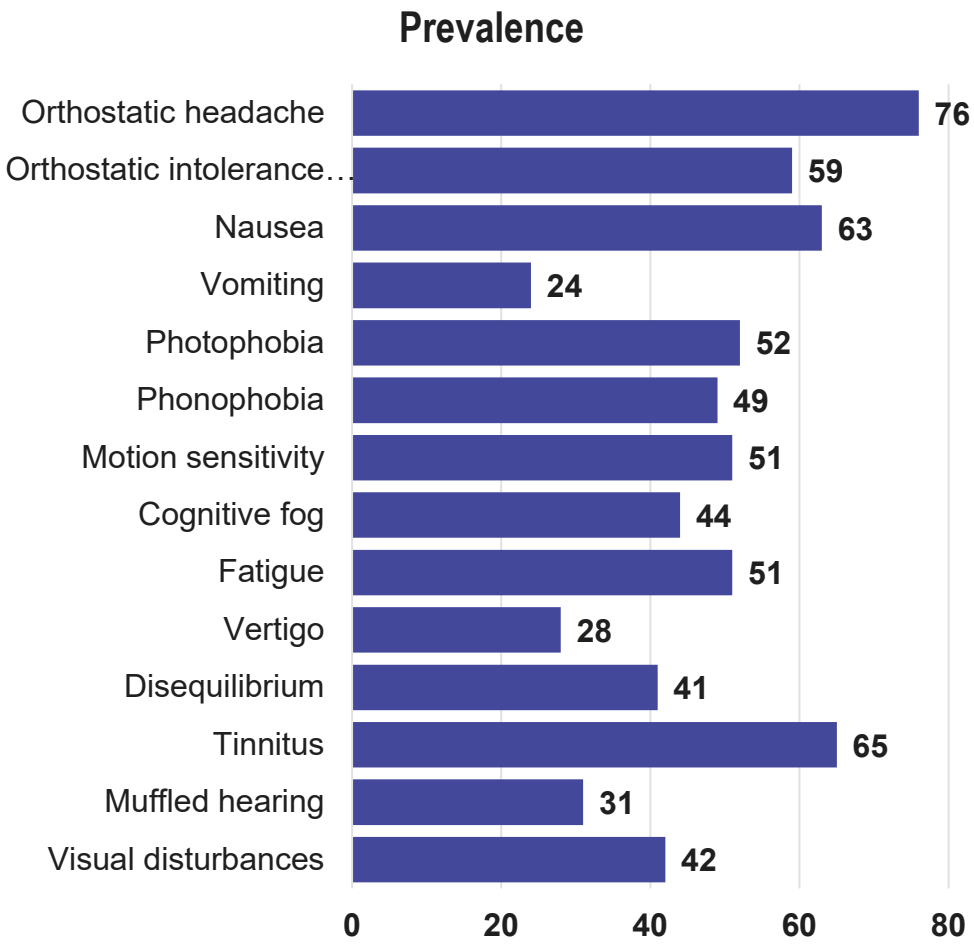
- **Constant tinnitus, hearing loss and aural fullness disrupt communication, sleep and concentration, increasing social isolation.**
- **Dizziness/light-headedness on standing leads to falls risk and avoidance of upright tasks**

Neck and Intrascapular Pain

[1] Mehta D et al. Cephalalgia 2025;45(1):1–10; [2] Cheema S et al. BMJ Open 2022;12:e057438; [3] D'Antona R et al. Headache 2024;64(5):1298–1308; [4] Amrhein TJ et al. J Patient-Reported Outcomes 2023;7:82

Clinical Features of SIH Contributing to Disability

Structured interviews with 137 patients to characterise SIH phenotype



Mehta D et al. Cephalalgia. 2025;45(1):1–10.

Nausea & Vomiting

- **Limits oral intake and upright tolerance; often tethered to headache episodes, compounding the need for bed rest.**

Cognitive Dysfunction (“Brain Fog”)

- **Impairs concentration, memory and multitasking—critical for work, driving and household management.**

Fatigue

- **Chronic low-energy state reduces endurance for daily activities even when headache abates.**

Visual Disturbances (e.g. Diplopia, Blurred Vision)

- **Double or blurred vision hinders reading, driving and fine motor tasks; diplopia from abducens palsy in ~30 %.[3]**

Sensory phobia

[1] Mehta D et al. Cephalalgia 2025;45(1):1–10; [2] Cheema S et al. BMJ Open 2022;12:e057438; [3] D’Antona R et al. Headache 2024;64(5):1298–1308; [4] Amrhein TJ et al. J Patient-Reported Outcomes 2023;7:82

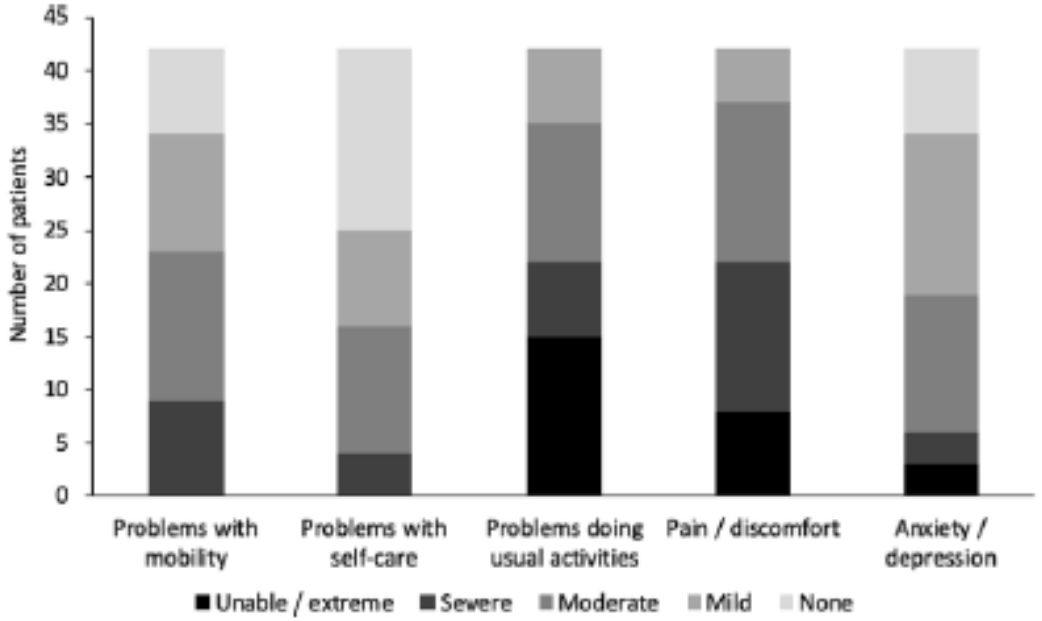
Quality of Life Matrix – Multi-Domain Impact

Multi-Domain Impairment:

- SIH wreaks havoc across **physical, emotional, and social domains** of quality of life (QoL)[1]
- Not just headaches; limitations in **mobility, self-care, usual activities, work, family roles, and mental well-being**.

Patient-Reported QoL Scores:

- **SF-36 Scores:** PCS 30.3; MCS 36.9 (norm = 50), significantly below population norms and worse than MS or IIH[2]
- **EQ-5D (UK Survey):**[1]
  - Usual activities: major problems in 84 %
  - Pain/discomfort: moderate–severe in 88 %
  - Mobility impairment: 54 %
  - Self-care difficulties: 39 %
  - Anxiety/depression: 45 %
- **15D Health-Related QoL:**
  - Mean index 0.890 in **treated SIH** vs 0.933 in general population (p = 0.001)[3]



1. Cheema S et al. BMJ Open 2022;12:e057438; 2. Liaw V et al. Neurology 2023;101:e2411–2422; 3.. Jesse CM et al. J Neurol. 2022;269:5466–5473

Mental Health Impact of SIH

High Rates of Depression & Anxiety

- Chronic pain and disruption lead to profound distress
- High levels of anxiety and depression reported

Study	Depression	Anxiety
USA Survey[1]	49%	25%
UK Survey[2]	55%	38%
Austrian Survey[3]	78%	97%

Hopelessness & Suicidality

- The prolonged odyssey can breed despair.
- USA cohort: 64.2 % "**wished to be dead**" and 22.4 % had engaged in **suicidal ideation or behaviour**[1].

Cognitive "Fog" & Emotional Strain

- **Memory lapses**, **difficulty concentrating**, and **health-related anxiety** are frequent; many describe ongoing frustration from delayed diagnosis[3,4].

Under-recognized Need for Support

- Despite overwhelming psychological burden, **fewer than 15 % of patients receive formal mental health referrals**, leaving most without adequate counselling or psychiatric care[2].

1. Liaw V et al. Neurology 2023;101:e2411–2422; 2. Cheema S et al. BMJ Open 2022;12:e057438; 3. Mehta D et al. Cephalalgia 2025;45(1):1–10; 4. Wolf KK, et al.Headache. 2025;65(2).

Occupational Impact of SIH

Severe Work Disruption:

- **UK Survey:** Over **50% modified duties** and **26 % lost jobs** due to SIH, as orthostatic headaches preclude regular schedules[1]
- **Austrian Survey** [2]
  - 15.1 % maintained **full-time employment**
  - 48.8 % reduced to **part-time roles**
  - 30.2 % **unable to work** at all
  - 5.8 % **took early retirement** due to SIH
- **Swiss & German Survey:** studied treated SIH patients[3]
  - 55% required ≥ 3 months sick leave; Mean sick leave 30 (± 40.3) weeks
  - 67% fully able to return to work
  - 23% not fully able to return to work
  - 10% early retirement

Consequences :

- **Economic**: Results in substantial individual and societal productivity loss
- **Identity**: Loss of role and career progression undermines self-worth
- Successful treatment often requires graded return-to-work and employer flexibility

1. Cheema S et al. BMJ Open 2022;12:e057438; 2. Kapan A et al. Wien Klin Wochenschr 2025;137:148–162; 3. Jesse CM et al. J Neurol. 2022;269:5466–5473

Social Impact of SIH

Family & Caregiver Strain:

- Chronic **disability shifts roles**—partners become caregivers or sole earners, often leading to emotional breakdowns[1]

Partnership & Marriage:

- 32 % report **severe negative impact on their relationship**; some cite feelings of burden, with **separations** or **divorces** (6%) occurring[1]

Social Isolation & Leisure Loss:

- 42 % experience **moderate-to-severe impairment in social activities**; friendships and hobbies wane as patients retreat for symptom control[1]

Life Disruptions:

- **Major lifestyle changes** (selling homes, career breaks) are common;
- "Life completely altered… Partner on career break to look after me," reflects extreme social and financial sacrifices[1,2]

Coping & Support:

- Peer support groups provide vital empathy and advice[2]

1. Jesse CM et al. J Neurol 2022;269:5466–5473; 2. Cheema S et al. BMJ Open 2022;12:e057438

Healthcare Utilization & Diagnostic Journey

Delayed Diagnosis:

- UK patients saw their GP a median 3× before referral; nearly 50% weren't diagnosed by the first specialist[1]
- US interviewees described delays of months to years before SIH was recognized[2]

Widespread Misdiagnosis:

- Over 90 % of UK patients were initially labelled with migraine, tension or sinus headache, or psychiatric causes[1]

Investigation and Treatment Delays:

- UK patients waited a median 4 weeks for brain MRI (range 0–56 weeks) and 2 weeks for EBP after referral (range 0–16 weeks)[1]

Invasive Imaging Gaps:

- In Canada, 43 % of SIH patients never received myelographic leak localization[3]

Specialist Access:

- In Canadian cohort:[3]
  - only 53.4 % ever saw a dedicated CSF-leak specialist (median wait 6–12 months)
  - 28% travelled out of country (mostly USA) for advanced diagnostics or treatments.

1. Cheema S et al. BMJ Open 2022;12:e057438; 2. Amrhein T et al. J Patient-Reported Outcomes 2023;7:82; 3.Hoydonckx Y et al. Can J Neurol Sci 2025;52:650–657

Economic Burden of SIH

Patient Financial Hardship

- 55 % of patients take ≥ 3 months sick leave[1]; 26 % lose their jobs[2]; only 15 % remain full-time[3]
- 67 % (UK) and 81.5 % (Canada) report **major personal financial strain**[2,4]
- 5 % of UK **patients fundraising**; many Canadians **pay out-of-pocket for imaging or surgery**[2, 4]

Healthcare System Costs

- High resource use: multiple MRIs, CT myelograms, repeated EBPs, hospital admissions and specialist visits[1,2]
- Misdiagnosis drives unnecessary procedures (e.g., sinus surgery, medical consults), adding to system expense[1]

Societal Productivity Loss

- Affects people in their prime working years; long-term disability in a small cohort equates to substantial GDP loss[2,4]
- Chronic income insecurity and career derailment also carry unmeasured, intangible costs to communities[1]

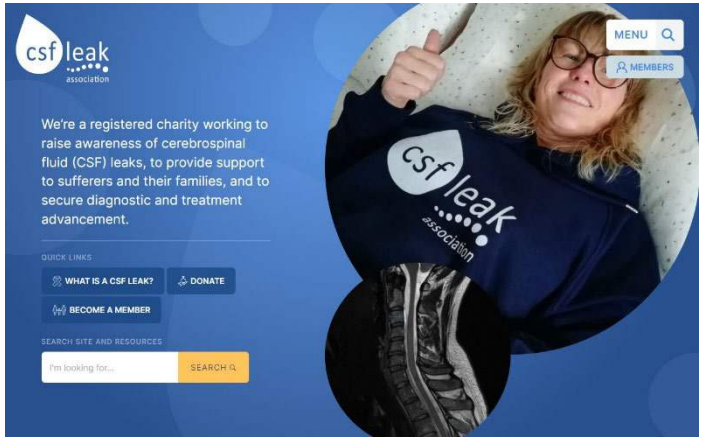
1. Jesse CM et al. J Neurol 2022;269:5466–5473 2. Cheema S et al. BMJ Open 2022;12:e057438; 3. Kapan A et al. Wien Klin Wochenschr 2025;137:148–162 ; 4. Hoydonckx Y et al. Can J Neurol Sci 2025;52:650–657;

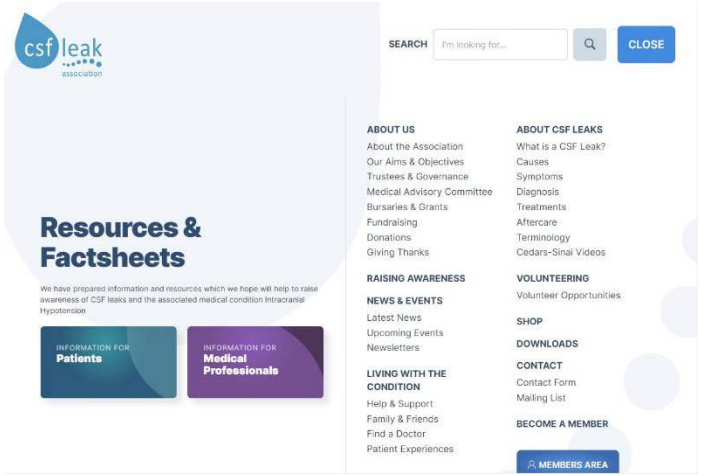
Patient Perspectives – Giving Voice to SIH Sufferers

Understanding lived experience is vital—statistics alone can't convey the daily struggles, despair, and resilience of those with SIH.

Listening to patients fosters empathy, improves care planning, and highlights needs beyond headache relief.

- ***"Life completely altered for me and my partner. Had to sell our business and move to smaller house. Partner currently on career break to look after me. We are severely restricted in finances and ability to live life. Don't see friends or family much."[1]***
- ***"I have lost my career… I am mostly bed-bound… just want to be able to work."[1]***
- ***"Doctors only see the tip. The wider impacts of a leak are numerous and severe, and support is all but non-existent."[1]***





Key Takeaway:

- Embedding patient perspectives ensures we address the emotional, social, and practical dimensions of SIH—not just the CSF leak itself.
- Partner with Patient Groups: Collaboration with advocacy organizations ensures care pathways, educational materials, and research priorities truly reflect patient needs.

1. Cheema S et al. BMJ Open 2022;12:e057438

Comparative Perspectives – UK, Canada & USA

United Kingdom (NHS)

Delayed Diagnosis & Misdiagnosis

- Patients saw GPs a median of 3× before referral; 46% not correctly diagnosed by first specialist[1]
- >90% initially misdiagnosed

Investigation & Treatment Delays

- Median wait for brain MRI 4 weeks; EBP arranged ~2 weeks after referral[1]
- Only 23% felt their pain management was adequate[1]

Canada

Access Barriers

- 88% consulted >1 physician; only 53% ever saw a CSF-leak specialist[3]
- Median wait to specialist: 6–12 months; 28% travelled (mostly USA) for treatment

Diagnostic Gaps

- Variable availability of dynamic CT/DSM across provinces

Treatment Hurdles

- 77% found care difficult to access[3]
- Many rely on out-of-pocket private MRIs and blood patches

USA

Geographic Disparities

- Many states lack any local SIH expertise—patients in rural or non-academic regions travel hundreds of miles simply to see a CSF-leak specialist.[2]

Insurance Hurdles

- Even with specialty centres available, pre-authorization requirements and network restrictions often delay diagnostics and treatments forcing patients to appeal or pay out-of-pocket.

Global Takeaways

- **Common Barriers:** Low SIH awareness, diagnostic delays, inconsistent workups, variable treatment access
- **Healthcare Trade-offs:** Single-payer systems (UK/Canada) → low direct cost but longer waits; mixed/ private U.S. → quicker care if insured; challenges with authorization

1. Cheema S et al. BMJ Open 2022;12:e057438; 2. Liaw V et al. Neurology 2023;101:e2411–2422; 3. Kapan A et al. Wien Klin Wochenschr 2025;137:148–162

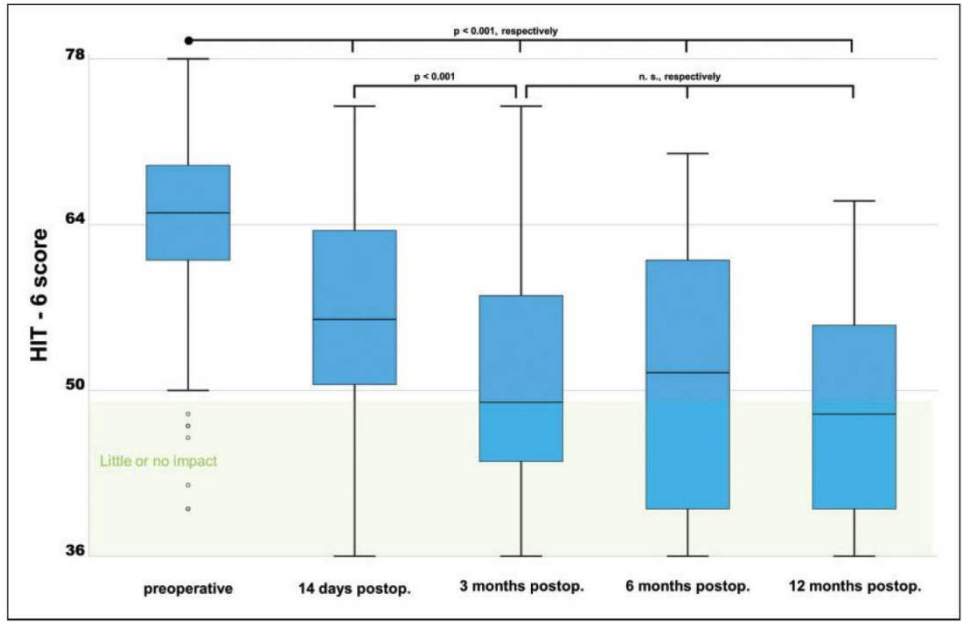
Quality of Life After Treatment

USA Study[1]

- 22 of 95 patients (23%) were symptom-free after treatment, while 73 remained symptomatic
- Symptom-free patients had significantly better scores: SF-36 PCS (44 vs 29), MCS (50 vs 34), HIT-6 (55 vs 67), PHQ-9 depression (5 vs 11)
- Successful treatment results in quality-of-life outcomes that approach or match those of the general population

German Study[2]

- 80 patients with spinal CSF leaks underwent surgery
- Headache disability scores (HIT-6) drop from 65 preoperatively to 49 at 3 months and remaining stable at 48 at 12 months



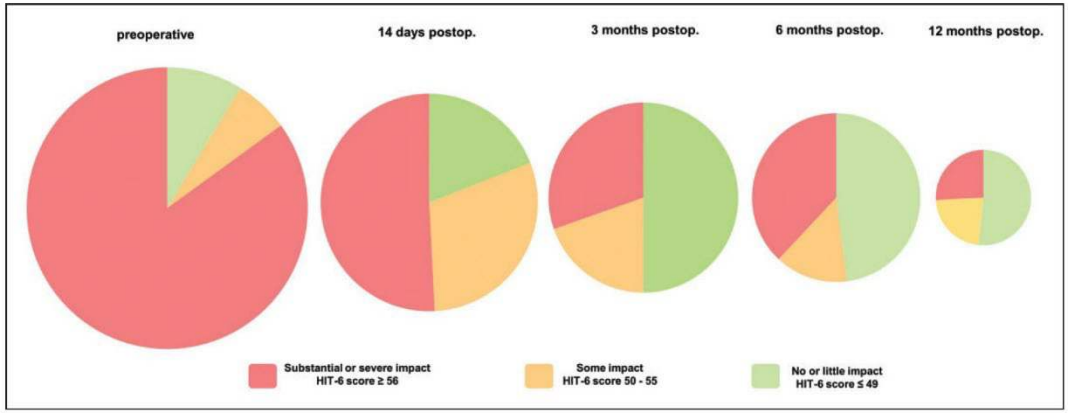
1. Liaw V et al. Neurology 2023;101:e2411–2422; 2. Volz F, et al. Cephalalgia. 2023;43(8):1–8

Quality of Life After Treatment

Residual Symptoms

German Study[1]

- 80 patients with spinal CSF leaks underwent surgery
- The proportion with severe headache impact (HIT-6 ≥56) fell from 85% before surgery to about 25% at one year, and orthostatic symptoms ('need to lie down') dropped from 79% to 23%; **a quarter of patients still have substantial symptoms**



Swiss & German Study[2]

- Of 69 surgically treated patients with spinal CSF leaks, 52% reported complete symptom resolution**, 41% had partial improvement, and about 5% had no improvement at all**
- Patients with complete resolution had a mean HRQoL (15D score) similar to the general population (0.938 vs 0.933), while those with residual symptoms remained significantly impaired (0.838)

1. Volz F, et al. Cephalalgia. 2023;43(8):1–8; 2. Jesse CM et al. J Neurol 2022;269:5466–5473

Key Takeaways

Sih's true impact is multidimensional

Timely, standardized care is critical

Treatment restores lives… but often not completely

A call for multidisciplinary, patient-centred models

- Integrate neurology, neuroradiology, pain/anaesthesia, neurosurgery, psychiatry and rehabilitation.
- Embed psychological support and patient advocacy from diagnosis through recovery.

Next steps for research & practice

- Develop and disseminate national/international SIH care guidelines.
- Build regional "leak centres" with streamlined cross-discipline pathways.
- Foster international registries to track long-term outcomes and refine best practices.
- Develop better investigative and therapeutic modalities

Domain	Key Impairments
Physical	Pain, Orthostatic dizziness, Fatigue, Mobility
Psychological	Depression, Anxiety, Cognitive "fog"
Social	Partnership strain, Social withdrawal
Occupational	Sick leave, Reduced work capacity, Financial burden

"When we listen to patients and act swiftly, we don't just patch leaks —we help people reclaim their lives."

Sex Differences in SIH

Female Predominance: Female: Male ratio 2:1

Delayed Male Presentation:

- In a 442-patient cohort, 32.1 % of men vs 19.9 % of women waited > 30 days for diagnosis[1].
- Men reported lower rates of nausea (55.8 % vs 67.1 %), vomiting (43.0 % vs 54.2 %), photophobia (9.7 % vs 17.0 %) and tinnitus (26.7 % vs 39.7 %)[1].

Higher SDH Risk in Men:

- SDH occurred in 29.7 % of men vs 10.8 % of women, with larger hematomas and more surgeries (OR 3.5)[1].

Treatment Response:

- First EBP non-response was 58 % in men vs 39 % in women (OR 2.2)[1].

Management Implications:

- Be especially vigilant with male SIH patients—monitor early for complications like SDH and pursue more aggressive diagnostic work-ups, earlier and/or repeated EBPs, and closer follow-up to optimize outcomes.

1. Lin P-T et al. Headache. 2024;64(5):1298–1308