

THE HIDDEN REALITY OF CHRONIC PAIN IN YOUTH



INTRODUCTION

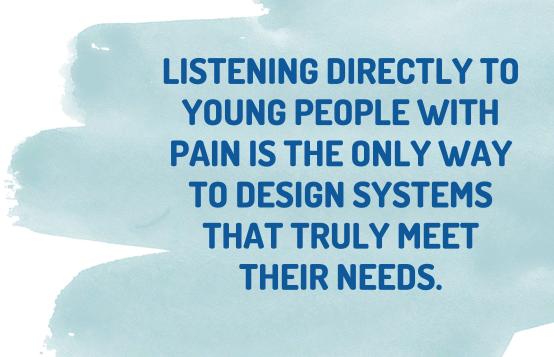
Children and teens' pain is often brushed aside as "growing pains" or exaggerations. But for many, pain is a daily reality that shapes school, friendships, and mental health. Yet despite its profound impact, pediatric chronic pain is often invisible, dismissed, and under-researched.

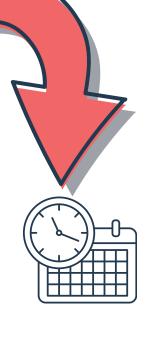
In May 2025, the U.S. Pain Foundation conducted the *Children, Teen, and Young Adult Pain Survey*, with 79 respondents ages 8–17. Through structured and openended questions, participants described persistent and disruptive pain, frequent disbelief from adults, and major gaps in medical and educational support.

Despite its small sample size, this survey revealed compelling findings and an urgent call to action. Listening directly to young people is the only way to design systems that truly meet the needs of youth living with chronic pain.



Separate survey reports explore adults with chronic pain, caregiver and parent experiences, and clinical perspectives.





KEY FINDINGS

The data reveal a powerful narrative: Pediatric pain is persistent, frequently dismissed, and profoundly disruptive. Key insights include:

- Chronic pain is long-lasting, and doesn't take a break.
 - Over 41% of youth reported living with pain for more than five years, and 53% said the pain never stops.



- Youth often feel disbelieved—especially by professionals.
 - Only 9% said they felt others always believed them when they talked about their pain. Teachers and doctors were rarely cited as sources of validation.



- School life is significantly disrupted.
 - 70% missed multiple school days each month; 20% received no accommodations, and 30% felt teachers didn't understand their needs.



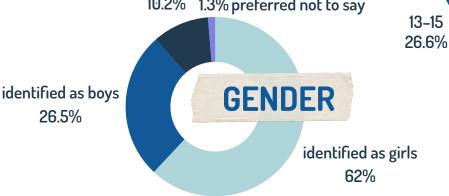
- Emotional and psychological strain is nearly universal.
 - Loneliness (89%), frustration (80%), stress (70%), and sadness (67%) were frequently reported.
- Simply having access to health care is not enough—youth need providers who truly understand.
 - Though 98% had seen a doctor, 65% found it hard to find one who understood their pain.

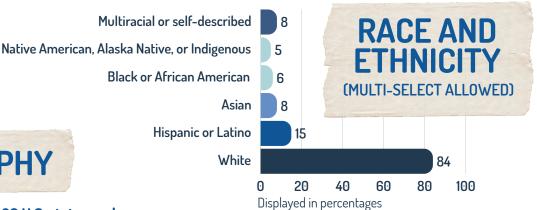
53% SAID THEIR PAIN NEVER STOPS.

DEMOGRAPHICS

Youth responding to the survey spanned a range of characteristics and identities.

nonbinary, gender-diverse, or self-described 10.2% 1.3% preferred not to say





8-12

21.5%

AGE

16-17 51.9%

GEOGRAPHY

Participants represented 26 U.S. states and Washington, D.C. (with two participating from outside the U.S.). The largest concentrations were from:

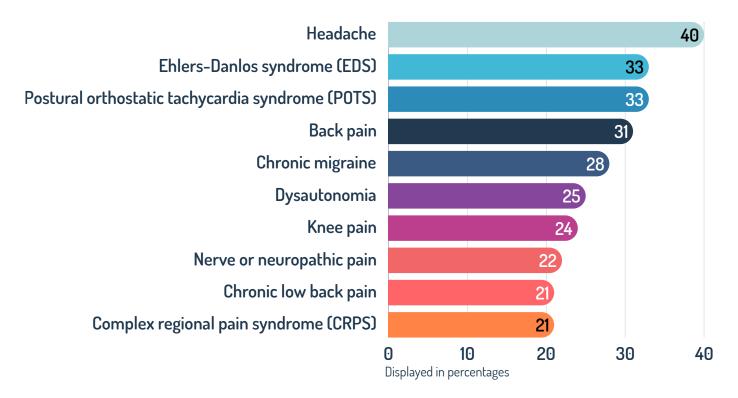
California: 15%

Texas: 24%

THE PAIN EXPERIENCE

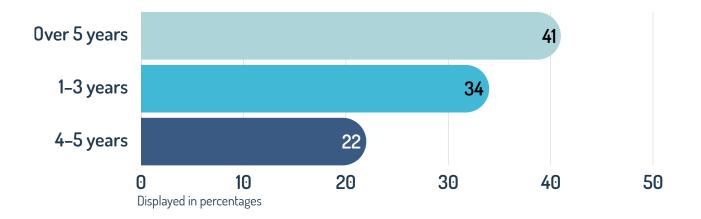
DIAGNOSES

85% of participants had doctor-confirmed pain conditions. Most common were:



Many also wrote in additional conditions, including **amplified musculoskeletal pain** syndrome (AMPS), mast cell activation syndrome (MCAS), and rare genetic syndromes.

DURATION OF PAIN



PAIN CHARACTERISTICS

Common Pain Locations

Joints: 63% Head: 58% Back: 53%

Stomach: 46%Muscles: 46%

• 43% reported "all-over" pain

How Pain Feels

• **Dull/achy:** 82%

Sharp/stabbing: 73%Burning/tingling: 60%

 Self-described pain sensations included: freezing, shocking, pulsing, squeezing, pulling, drilling, radiating, twisting

Pain Frequency

• 53% reported pain that **never stops**

• 46% said it comes and goes

Top Pain Triggers

• Certain movements: 85%

• Standing: 71%

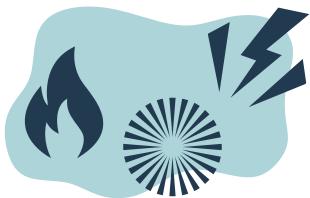
• Stress: 67%

• Weather changes: 62%

• Sitting too long: 60%

• Lack of sleep: 56%





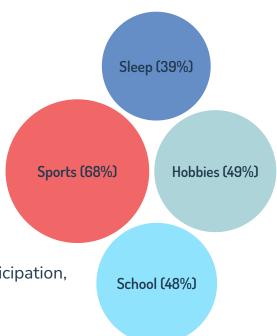




Additional factors that caused or increased pain included **bright lights**, **loud sounds**, **certain foods**, **certain types of clothes**, and **screen exposure**—illustrating how lifestyle and environmental conditions compound medical issues and **amplify the pain burden**.

THE IMPACT OF PAIN

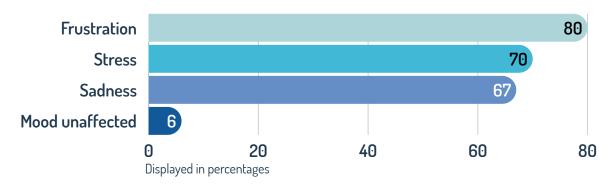
Chronic pain shapes nearly every aspect of daily living for young people—affecting their mental health, impacting their relationships, and disrupting their ability to participate fully in life.



Physical and Functional Limitations

Respondents reported that pain limited their participation, attendance, or capacity in the following areas:

Emotional Consequences



Open-ended responses revealed themes of hopelessness, isolation, overwhelm, embarrassment, fear, not being good enough, and grief.

Loneliness

Social disconnection emerged as a commonality:



THE IMPACT OF PAIN









Belief and Support

- Only 9% felt others always believed their pain
 - 19% said they were rarely or never believed
 - 61% said they were **believed "sometimes"**
- Most (75%) cited parents, guardians, or caregivers as their primary source of belief and support
 - 10% listed friends
 - 4% cited siblings
- Feeling unheard: **1** in **5** had **no one to talk to** about their pain

Coping Methods

- 44% watched **TV or movies**
- 29% engaged in art projects
- 17% each turned to **reading**, **music**, **Legos**, or **video games**
- Others mentioned pets, friends, rest, and using weighted blankets

Confidence in Managing Pain

- 27% felt they **knew what to do** during a pain episode
 - 57% said they knew what to do "sometimes"
 - 17% did not know what to do at all

Peer Support Participation

Peer support group participation was generally underutilized; **34%** had joined a group. Of those:

- 41% found it very helpful
- 52% somewhat helpful
- 7% not helpful

EDUCATION, SCHOOLING, AND ACCOMMODATIONS

Pain-related challenges were reflected in educational disruptions and alternative schooling arrangements.







Mode of Schooling

- 60% attended in-person
- 27% were homeschooled
- 8% followed a hybrid model
- 4% were hospital-homebound
- 3% were not enrolled in school

Absenteeism

- 28% missed 2–4 days per month
- 26% missed 5–6 days per month
- 15% missed 7 or more days per month
- Just 13% said they don't miss school due to their pain

Disclosure of Pain

- 75% disclosed their condition to teachers or staff
- 16% relied on parents for disclosure
- 9% did not disclose their condition at all

Accommodations Received

While many respondents (75%) reported receiving at least some school-based accommodations, 1 in 5 did not have accommodations in place.

- These accommodations were most commonly listed as helpful:
 - Less physical activity required (45%)
 - Flexible schedules or extended time for assignments (33%)
 - Rest or breaks at school (29%)
 - o Direct support from staff (e.g., teachers, counselors, nurses) (26%)
 - Access to staff elevators (24%)

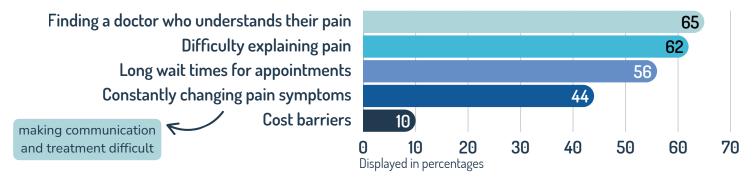
Understanding from Adults and Peers

Youth living with chronic pain described inconsistent levels of empathy and understanding from teachers and peers:

- 30% reported that no teachers understood their experience
- Just 3% felt peers completely understood their pain; another 22% said peers made an
 effort to understand

HEALTH CARE ACCESS AND TREATMENT BARRIERS

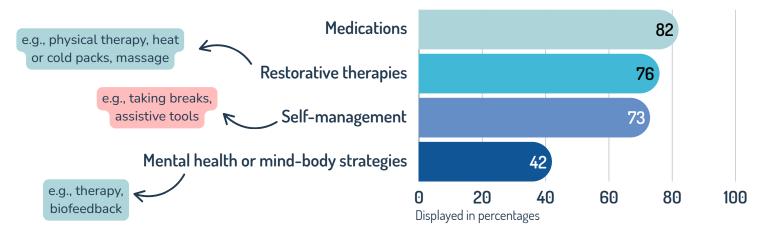
Most youth **(98%)** had seen a doctor for pain-related concerns. Yet significant barriers in access, communication, and trust remain. Respondents reported the following challenges:



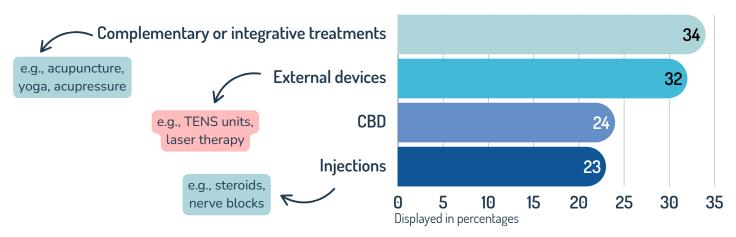
More than a third (35%) reported facing a lack of belief from adults, highlighting the stigma around pediatric pain.

Treatments Attempted

The most commonly used treatments were:



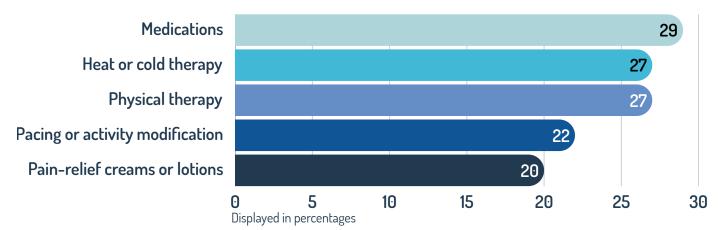
Several additional interventions were used by smaller segments of the population:

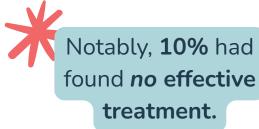


HEALTH CARE ACCESS AND TREATMENT BARRIERS



Respondents highlighted the following treatments as being most beneficial:





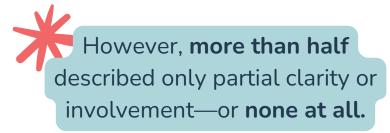
Communication and Decision-Making

Doctor explained treatment options clearly

Felt included in decision-making about their care

0 10 20 30 40 50

Displayed in percentages



IN THEIR OWN VOICES

Key themes emerged from children and adolescents' narrative responses.

"If I was going to choose an illness, I would choose something people believed."

"I'm not just being dramatic. Something is wrong."

Need for Validation: Being Seen, Heard, Believed, and Taken Seriously



"It's hard to know how to describe it at times because I get so used to having it." "I learned very quickly that no one wants to hear about my suffering, and that my illness makes others uncomfortable."

Difficulty Communicating the Complexity of Pain

"When we talk to you about our pain, listendon't just pretend to."



"Drinking water and going to therapy doesn't fix everything."



"Chronic means chronic. If there was a magic fix, I wouldn't be in this situation."

Frustration with Treatment and Medical Responses

"We need doctors to focus on pain reduction, not fixing the issue."

IN THEIR OWN VOICES

"Most school systems don't understand chronic pain the way they understand other diagnoses."

"I have to drive 6 hours away to see a doctor." Kids and teens shared the challenges they face—and what they need.

Systemic Barriers in Schools and Health Care

"I wish I had a group to go to, so I could meet kids like me."

"Opening up is hard, but when you do it, it's very helpful and rewarding."

A Call for Peer Connection—and Support Without Judgment



"Going to chronic pain camp made me feel seen."

RECOMMENDATIONS













Improve Provider Education and Validation of Pediatric Pain

Train clinicians to recognize and respond to chronic pain in youth—especially when it is invisible, fluctuating, or difficult to describe.

Broaden Access to Multimodal, Individualized Treatment Plans

Ensure availability of diverse, age-appropriate therapies—including mental health, physical, complementary, and experimental options—and expand pediatric-focused pain research.

Enhance Communication and Shared Decision-Making in Care

Encourage clinicians to clearly explain treatment options and actively involve youth in decision-making.

Integrate School-Based Accommodations and Awareness Programs

Increase training for educators and provide flexible supports like time or space to rest, modified schedules, and reduced physical activity requirements.

Invest in Peer Support Networks and Community Programs

Expand programs like family pain camps, peer support groups, and online communities.











CONCLUSION

These findings reveal a clear and urgent truth. Chronic pain in youth is not rare, imagined, or temporary—it is **real**, **ongoing**, **and deeply disruptive**. Even when communicating clearly what hurts and what helps, young people often face disbelief, delays, and limited choices in both medical and educational systems. They don't want pity, just help: to be heard, believed, and supported in ways that **reflect the gravity of their experience**—and that **center them in decisions about their care**.

This report offers more than data; it shares the voices of children who are **navigating pain with resilience and insight**. Their recommendations illustrate opportunities for practical and compassionate change: clearer communication, more-diverse treatments, peer connection, and informed adults who **respond with empathy instead of doubt**.

These findings serve as both a mirror and a mandate. The question is no longer whether children with pain need more support—it is if they will receive it, and when.

YOUTH WITH PAIN DON'T WANT PITY, JUST HELP: TO BE HEARD, BELIEVED, AND SUPPORTED.

