U.S. PAIN
FOUNDATION

THE HIDDEN STRUGGLES AND NEEDS OF CHRONIC PAIN CAREGIVERS

U.S. PAIN FOUNDATION
2025 NATIONAL SURVEY

EXECUTIVE SUMMARY

Alongside the 1 in 4 adults in the United States living with chronic pain are their caregivers or care partners —often unpaid or unsupported—who carry an often heavy but invisible burden. In May 2025, the U.S. Pain Foundation conducted a national survey of 2,420 individuals, including those living with chronic pain, caregivers, parents of children with pain, and health care professionals. This report consolidates findings from the 107 individuals who completed the caregiver-specific section of the survey.

These caregivers are overwhelmingly unpaid, under-supported, and emotionally and physically burdened. They are essential actors in health care delivery, yet receive none of the training, recognition, or resources required to sustain their roles over the long term. Their insights highlight a public health failure and an urgent call to action for policymakers, health systems, and community leaders.

UNPAID, UNDER-SUPPORTED, AND BURDENED—CAREGIVERS CARRY AN INVISIBLE WEIGHT THAT THE HEALTH SYSTEM TOO OFTEN IGNORES.

KEY FINDINGS AND IMPLICATIONS

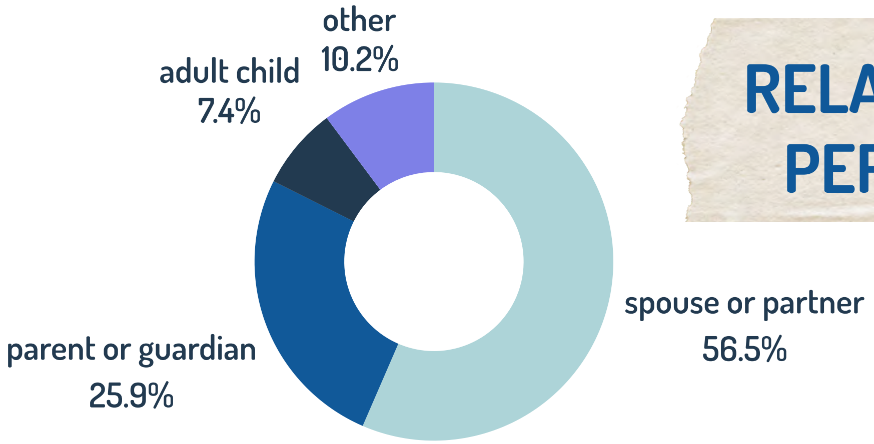
Theme	Key Statistics	Implications
Mental Health	94% reported mental or emotional strain	Psychological distress is an inextricable part of caregiving
Physical Health	85% reported physical strain	Caregivers' health is at risk
Burnout	82% felt overwhelmed	Caregiving is reaching unsustainable levels
Financial Strain	60% experienced financial hardship	Economic burden is profound and under-acknowledged
Access to Support	81% lacked adequate resources or support	Caregivers are underserved by current systems
Caregiver Preparedness	Only 31% felt adequately trained	Most lack the tools to manage care effectively
Peer Support Needed	83% expressed interest in peer groups	Demand for scalable, community-based interventions
Dual Burden	43% also live with chronic pain	Many caregivers face compounded physical and emotional strain

CAREGIVING IS ESSENTIAL BUT UNSUSTAINABLE WITHOUT URGENT INVESTMENT IN TRAINING, SUPPORT, AND COMMUNITY RESOURCES.

DEMOGRAPHIC AND ROLE CHARACTERISTICS

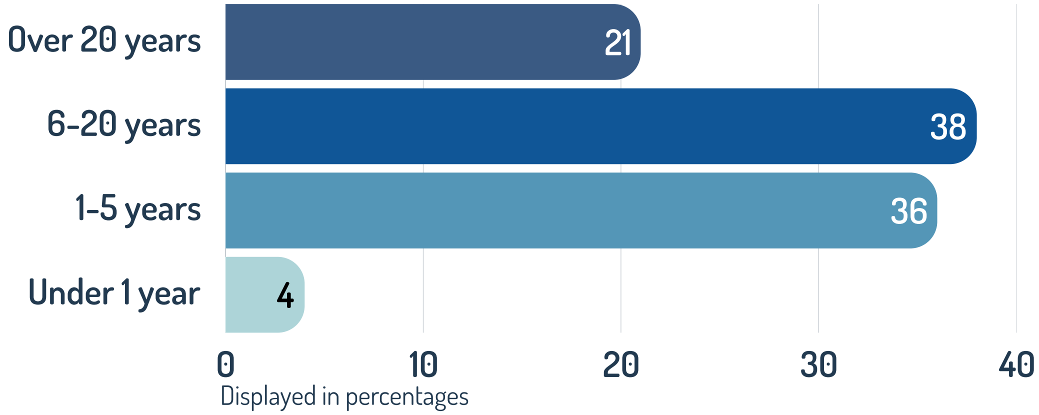
Caregiving is not a temporary function—it is often a multi-decade, unpaid commitment.

RELATIONSHIP TO THE PERSON WITH PAIN



DURATION OF CAREGIVING

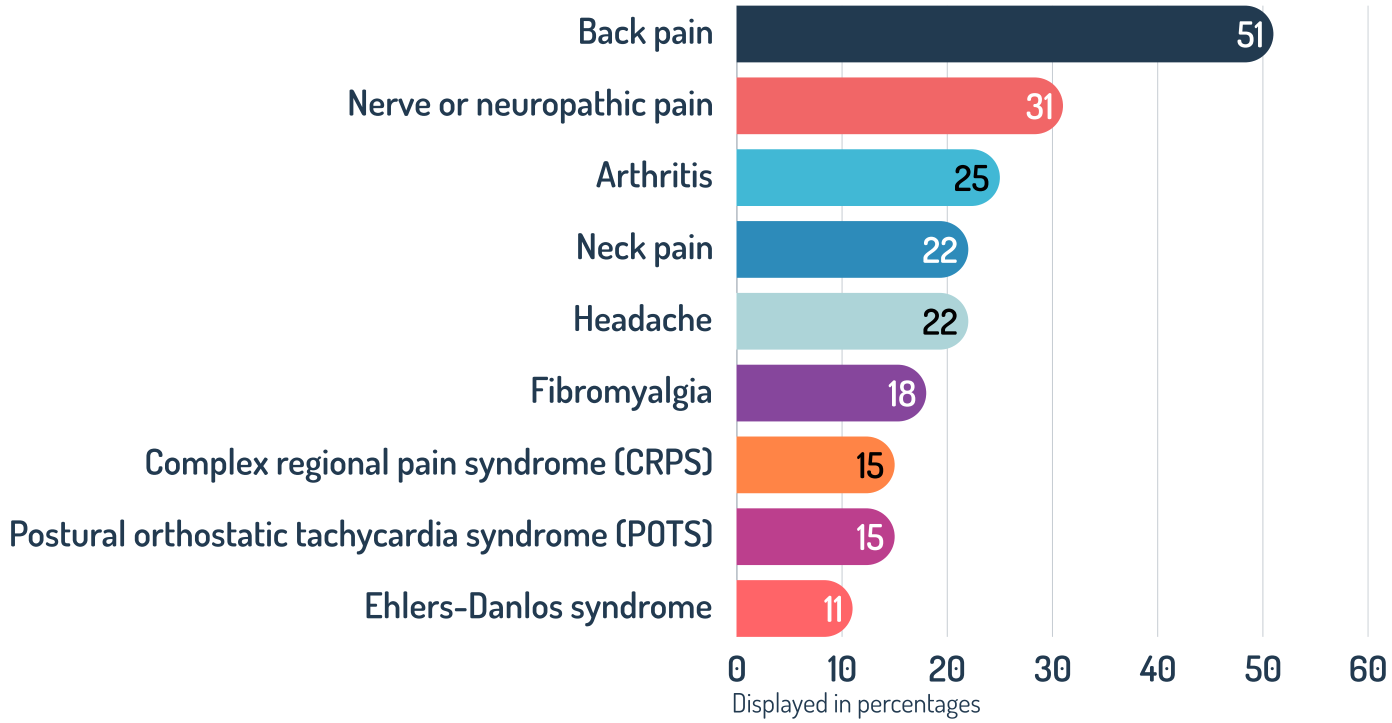
MORE THAN HALF PROVIDE CARE FOR OVER 16 HOURS A WEEK, WITH 28% PROVIDING CARE FOR 30+ HOURS



“WE NEED RESPITE CARE THAT DOESN’T COST AN ARM AND A LEG.”

CHRONIC PAIN CONDITIONS BEING MANAGED

Caregivers supported a diverse range of conditions, often overlapping and complex:



EMOTIONAL, PHYSICAL, AND SOCIAL TOLL

Caregivers are experiencing severe psychological and physical impacts:

- **86%** struggled to balance caregiving with personal time
- **77% reported major life disruptions:**
  - Altered social or recreational activities **(87%)**
  - Reduced working hours or had to stop working **(56%)**
  - Moved to accommodate loved one's health needs **(20%)**
- **59%** cited lack of time for self-care
- **57%** reported physical difficulty with the demands of caregiving
- **34%** lacked support from family and friends

ONLY 14% ACHIEVED ANY DEGREE OF PERSONAL BALANCE

ECONOMIC IMPACT

ONLY 2% OF ALL RESPONDENTS REPORTED RECEIVING ANY FORM OF FINANCIAL AID

- **60%** reported financial hardship
  - **73%** have lost income
  - **73%** incurred increased medical costs
  - **56%** faced transportation-related costs

CAREGIVER TRAINING AND HEALTH CARE NAVIGATION

- **69%** felt unprepared to manage their loved one’s chronic pain conditions
- **58%** reported difficulty navigating the health care system
- **35%** cited difficulty managing medications and treatments

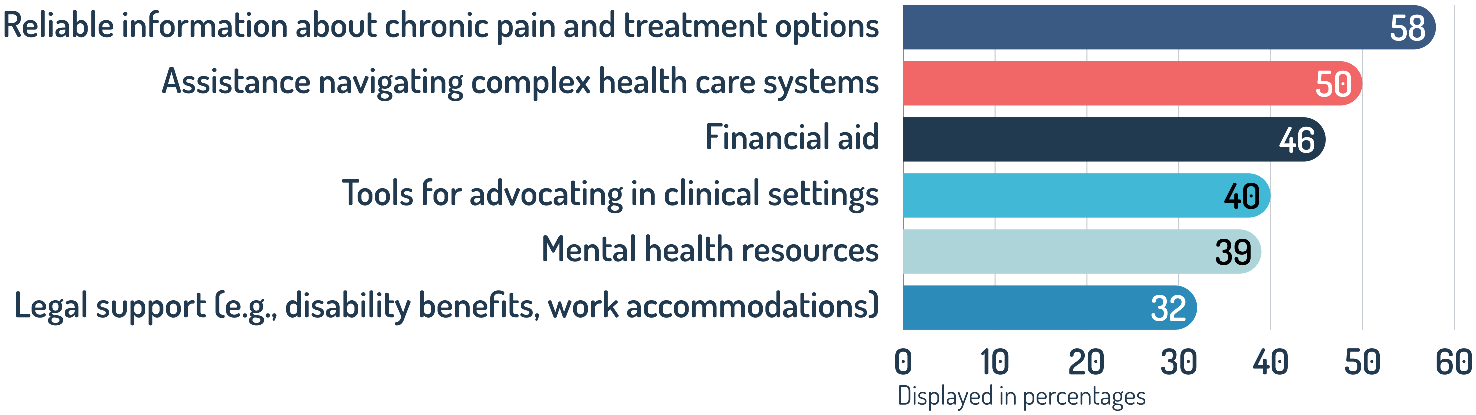
Top requested educational resources:

- Emotional and mental health care for caregivers (**64%**)
- Pain management techniques (**61%**)
- Self-care strategies for caregivers (**46%**)
- Communication tools for engaging with health care providers (**45%**)
- Condition-specific education (**41%**)
- Medication management and safety (**37%**)

GAPS IN SYSTEMIC AND COMMUNITY SUPPORT

Only 19% of caregivers or care partners felt they had sufficient resources to fulfill their role.

Top unmet support needs



> “WE NEED MEDICAL STAFF THAT WOULD TAKE THE TIME TO LOOK AT THE BIG PICTURE IN A VERY COMPLICATED CASE.”

COPING STRATEGIES AND PEER SUPPORT DEMAND

Most-used coping strategies:

- Self-care practices (64%)
- Talking to family or friends (61%)
- Relaxation techniques (35%)
- Counseling or therapy (28%)

Peer connection emerged as a key interest area—**83% expressed interest in joining support groups**, with preferred features including:

- Compassionate participants and experienced facilitators
- Access to practical information
- Confidentiality
- Flexible participation formats

15% HAVE NOT FOUND ANY COPING STRATEGY HELPFUL—OR HAVE NOT ATTEMPTED ANY.

> **“AS A CAREGIVER OF A CONDITION THAT WAS NOT WELL RECOGNIZED, I HAVE TO FIGHT FOR EVERY LITTLE NEED, AND BASICALLY FOR OUR RIGHTS.”**

STRATEGIC RECOMMENDATIONS

Policy and Financial Infrastructure

- Fund direct caregiver compensation and support stipends
- Recognize caregiving in tax, employment, and retirement systems
- Expand eligibility for paid leave and financial relief programs

Education and System Navigation

- Offer caregiver-specific training on pain management, communication, and medication safety
- Create tools for navigating pain and the health care and insurance systems

Mental Health and Respite Care

- Invest in low-cost, accessible mental health services for caregivers
- Establish and fund respite care infrastructure
- Train clinicians to work collaboratively with caregivers, and to recognize and help address caregiver burnout

Peer and Community-Based Interventions

- Expand flexible, peer-led caregiver support groups
- Train peer facilitators and provide practical, evidence-based materials
- Ensure confidentiality and low-barrier access to participation

ADDRESSING EQUITY AND REPRESENTATION

Although this section of the survey did not collect race, ethnicity, or other identity-based demographics, it is critical to acknowledge that caregivers from marginalized communities face additional barriers—including racial or gender identity-based bias in health care, less access to insurance, and culturally unresponsive services. Future research and programmatic interventions must center equity and inclusion as foundational components.

> **“PHYSICIANS ASSUME MY LOVED ONE IS DRUG-SEEKING. I NEED HELP TALKING TO THEM. I NEED TO BE BELIEVED, TOO.”**

CONCLUSION

Caregivers and care partners of individuals living with pain remain an often unseen yet foundational component of chronic pain management. They provide sustained emotional, physical, and logistical support—often for years or decades—without adequate recognition, training, or financial assistance, and frequently while living with pain of their own. The findings of this survey offer clear and urgent evidence of widespread burnout, financial hardship, and marginalization.

Improving outcomes in chronic pain care requires including caregivers in the national strategy. It is imperative that our health care system ensures access to mental health services, caregiver-specific training, peer support systems, financial assistance, and active inclusion in research, clinical care, and the policy-making process. Without such systemic changes, caregivers will continue to shoulder enormous responsibility without the resources necessary to sustain themselves or the people they care for.

> **"I NEED ASSISTANCE IN COMMUNICATING WITH DOCTORS, GETTING THEM TO TRULY UNDERSTAND CHRONIC PAIN—THE IMPACT ON BOTH THE PATIENT AND CAREGIVER."**

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