SPF HSP/PLS Patient History Survey Report

SPF SPASTIC PARAPLEGIA FOUNDATION, INC.

RESEARCH | EDUCATION | SUPPORT

HEREDITARY SPASTIC PARAPLEGIA
PRIMARY LATERAL SCLEROSIS

#HSPandPLS

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The Patient Voice in Action

OCTOBER 2025

MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR

On behalf of the Spastic Paraplegia Foundation (SPF), we extend our heartfelt gratitude to every individual and family who shared their story through this survey. Your voices are powerful, and they are now helping to shape critical conversations with the NIH, FDA, researchers, and industry leaders. Together, we are laying the foundation for a roadmap that will guide us toward the therapies and cures our community urgently needs and deserves.

The results of the 2025 SPF HSP/PLS Patient History Survey deliver a resounding message: people living with HSP and PLS face the daily burdens of progressive symptoms, the lack of approved therapies, and the uncertainty of what lies ahead. Yet, through your participation, you have transformed these challenges into data and testimony that speak directly to those in a position to change the future.

This survey is far more than statistics—it is the collective voice of patients and families demanding recognition, research, and results. It underscores the urgent need for regulators, scientists, and industry partners to work together, accelerate therapeutic development, and seize opportunities such as drug repurposing, biologics, and other therapeutics to bring treatments more quickly to those who cannot wait.

The findings highlight the pressing unmet needs of our community and the clear opportunities for action: to advance drug development, expand clinical trials, and ensure that no person living with HSP or PLS is left without hope for treatment.

With determination and hope,
Greg Pruitt
President, Spastic Paraplegia Foundation, Inc

Norma Pruitt
Executive Director, Spastic Paraplegia Foundation, Inc.

October 2025

Introduction

The Spastic Paraplegia Foundation (SPF) is honored to present the findings of the 2025 SPF HSP/PLS Patient History Survey, the most comprehensive effort to date to capture the voices and lived experiences of individuals and families affected by Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS).

Since its founding in 2002, SPF has worked to advance research, accelerate therapy development, and provide support for people navigating the challenges of these rare motor neuron diseases. Yet, despite decades of effort, there remains no FDA-approved treatment specifically for HSP or PLS. This reality underscores the urgent need for collaborative action—by researchers, clinicians, regulators, pharmaceutical partners, and, critically, by the patient community itself.

On June 13, 2025, SPF launched the 2025 SPF HSP/PLS Patient History Survey with a singular purpose: to center the voices of those most affected by Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). These ultra-rare motor neuron disorders present a significant burden on physical function, quality of life, and access to care—yet real-world patient experiences often remain invisible to those shaping the future of research, regulation, and policy.

On July 20, 2025, SPF paused the survey outreach to compile the information. The report compiles the firsthand insights of over 770 individuals living with or caring for someone with HSP or PLS. It is the most comprehensive survey effort ever undertaken by SPF. The insights gathered here are more than statistics. They are a call to action for pharmaceutical partners, key opinion leaders, clinicians, and regulators—including colleagues at the National Institutes of Health (NIH), the U.S. Food and Drug Administration (FDA), the Critical Path Institute (C-Path), the Spastic Paraplegia Center of Excellence Research Network (SP-CERN), academic researchers, and biotechnology innovators working to translate science into solution —to accelerate efforts that bring meaningful treatments to our community.

This survey was designed to ensure that the voices of patients and caregivers are not only heard, but placed at the center of conversations that shape the future of therapeutic discovery, regulatory pathways, and clinical research. Every response reflects the challenges, resilience, and daily realities of people living with these chronic, rare motor neuron diseases. Together, these voices form a unified message: the urgent need for effective therapies, and ultimately, cures.

Equally important, this survey empowers patients and caregivers by ensuring their perspectives are central to the scientific and regulatory dialogue. Too often, rare disease communities face fragmented data collection—small, siloed studies that are difficult to scale or share. By contrast, the SPF HSP/PLS Patient History Survey brings the community together, offering a unified, accessible resource to drive progress.

The findings in this report are intended for multiple audiences:

- Patients and families, who will see their stories reflected in the collective voice of the community.
- Researchers and clinicians, who will gain valuable insights to guide therapeutic development.
- Regulators and policymakers, who will better understand the daily impact of HSP/PLS and the urgent need for solutions.

- Pharmaceutical and biotech partners, who can use this data to shape drug development biologics and programs with meaningful, patient-relevant outcomes.

The survey results are also being shared directly with key opinion leaders, patients and families, clinicians, pharmaceutical partners and regulators, and key stakeholders like the National Institutes of Health (NIH), the Food and Drug Administration (FDA), the Critical Path Institute (C-Path), the Spastic Paraplegia Center of Excellence Research Network (SP-CERN), academic researchers, and biotechnology innovators as part of a broader roadmap to accelerate therapy development. This report also serves as an important foundation for discussion at the 2025 SPF Annual Conference in Washington, D.C., where patients, researchers, regulators, and policymakers will gather to review the findings, align on priorities, and map out next steps in therapy development.

We are deeply grateful to every patient and family member who took the time to share their experiences. Your courage and openness have created a lasting resource that will guide research, inform policy, and bring us closer to treatments and cures.

This publication represents not just data, but a collective call to action. Together, we can and must turn these lived experiences into meaningful change.

ABOUT THE SURVEY

The 2025 SPF HSP/PLS Patient History Survey is the most comprehensive data collection effort to date for individuals and families affected by Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). This survey was created and led by the Spastic Paraplegia Foundation (SPF), with results shared broadly across the research, regulatory, and patient community to accelerate progress toward treatments and cures.

- Respondents: The majority of responses (87.5% of 770) were provided by patients, ensuring the survey reflects their direct lived experiences.
- Geography: Survey respondents from 32 countries across the world were identified: United States of America, Argentina, Australia, Austria, Bangladesh, Belgium, Brazil, Canada, Denmark, Finland, France, Germany, Great Britain, India, Ireland, Israel, Italy, Hungary, Netherlands, New Zealand, Norway, Poland, Portugal, South Africa, South Korea, Spain, Sweden, Switzerland, Turkey, United Arab Emirates, United Kingdom, Venezuela. The SPF Member Database includes members from 65 countries.
- Focus: Symptoms, progression, quality of life, daily function, and treatment experiences.
- Purpose: To provide a patient-driven evidence base for researchers, regulators, and industry, ensuring that lived experience shapes therapy development and clinical trial design.

Although fewer individuals with PLS completed the survey, their responses reveal that symptoms are experienced differently compared with HSP patients, often presenting unique challenges. This underscores the need for continued research and increased participation from the PLS community to better understand their lived experience. It is important to note that the survey window for SPF members

was only 37 days, which limited participation to 770 respondents. This rapid-response requirement underrepresents the full population within our community and highlights the need for broader, targeted outreach. The following two tables illustrate how the survey responses compare to the SPF Member Database:

Category	United States	International	Total	Survey Total
Primary Lateral Sclerosis (PLS)	1192	84	1276	142
Hereditary Spastic Paraplegia (HSP)	3942	805	4747	628
Tropical Spastic Paraplegia (TSPG)		12	12	0

Location	HSP	PLS	Total	Survey Total
United States	3942	1192	5134	486
Other Countries	341	24	365	193
United Kingdom	208	21	229	12
Brazil	108	18	126	54
Australia	88	18	106	15
India	60	3	63	10

BY THE NUMBERS – KEY FINDINGS FROM THE 2025 SPF HSP/PLS PATIENT HISTORY SURVEY

What This Means

The results of this 2025 SPF HSP/PLS Patient History Survey paint a clear and urgent picture: individuals and families affected by HSP and PLS are living with progressive symptoms, daily challenges, and no approved therapies. The collective patient voice captured here underscores the critical need for regulators, researchers, and industry partners to take immediate action. By expanding clinical trials, accelerating therapeutic development, and prioritizing drug repurposing opportunities, we can begin to close the gap between mechanistic science and real-world treatments. This data is more than numbers— it is the lived experiences of a rare disease community calling for progress, partnership, and hope.

- **No FDA-approved treatments** for HSP or PLS exist today

- **Loss of Mobility: A Resounding Cry for Help**
  For individuals living with HSP or PLS, the most devastating and universal challenge is the relentless loss of mobility. The data reveal an overwhelming reality:

  - **94.2%** struggle with walking, stumbling, or tripping.
  - **92.3%** endure stiffness and spasticity in their legs.
  - **85.6%** face balance and coordination difficulties.
  - **81.8%** report progressive leg weakness.
  - **73.9%** experience bladder and bowel dysfunction, adding further indignity and burden.

Taken together, these findings underscore a profound truth: nearly every patient experiences daily erosion of independence. The inability to walk safely, control one's body, or maintain dignity in basic functions is not simply a medical issue—it is a resounding loss that reverberates through families, work, school, and social lives.

Patients and families describe this loss of mobility as the most crushing aspect of their condition. Without effective treatments, every stumble, every fall, and every new limitation marks a progression toward dependence. These are not abstract numbers, but urgent reminders that research and therapeutic development cannot wait.

- **Lives Defined by Wheels and Supports**
  For the HSP/PLS community, the progression of symptoms often leads to an unavoidable dependence on assistive devices. What begins with a cane or walking poles too often advances to walkers, wheelchairs, and scooters—symbols not of freedom, but of what has been lost.

  - **Nearly half of respondents (45%)** rely on a walker to move even short distances.
  - **Four in ten (40%)** depend on a wheelchair, underscoring the severity of mobility loss.
  - Many attempt to delay decline with **canes (31%)** or **walking poles (21.5%),** yet the progression continues.
  - **Scooters (17.4%)** represent another adaptation to maintain independence, but also a reminder of the relentless advance of these diseases.

Patients and families describe this reliance not as choice, but as necessity—each device a marker of disease progression. The data illustrate a stark reality: **without approved therapies, mobility fades, independence erodes, and patients are left to desperately rely on equipment rather than treatment.**

- **Exhausting Every Option, Yet Still Without Relief**
  For people living with HSP and PLS, the path through medical care is long, exhausting, and too often discouraging. Nearly every respondent (**97%**) reported seeing a neurologist for their symptoms, and most (**82.9%**) have also sought physical therapy. Across the community, patients identified **349 different specialists** they have turned to for help. Despite this effort, the best treatments currently available remain **physical therapy** and **Botox injections**—valuable but limited in their impact.

The survey reveals the breadth of interventions patients are already using:

- **83.2%** rely on physical or occupational therapy, often as a lifelong commitment rather than a short-term course.
- **81.5%** use medications, such as baclofen, to temporarily ease spasticity but rarely achieve sustained relief.
- **82.0%** require assistive devices, underscoring the inevitability of mobility loss without better therapies.
- **82.0%** undergo surgeries or medical procedures, yet outcomes are inconsistent and rarely transformative.

This data reflects the desperation of families who are willing to try anything—often juggling multiple therapies at once—while knowing none will alter the course of the disease. The clear message: **we urgently need clinicians and researchers to expand beyond the status quo, to pursue new strategies, repurpose promising drugs, biologics, and explore innovative interventions that can finally change the trajectory of HSP and PLS.**

- **A Relentless Search for Care Without Lasting Solutions**
  The HSP and PLS community is doing everything possible to seek answers from the medical system—but too often, the search leads to management, not meaningful relief. Survey respondents reported seeing a wide range of specialists:

- **97.0%** have seen a neurologist, reflecting the obvious central role of the nervous system in these diseases.
- **82.9%** have engaged physical therapists, often committing to lifelong regimens just to maintain a basic level of function.
- **40.5%** sought care from urologists to manage bladder and bowel dysfunctions that strip away dignity and independence.
- **33.3%** have turned to occupational therapists in efforts to preserve daily living skills.
- **31.3%** have required the support of psychologists, therapists, or counselors to cope with the mental health toll of progressive disability.

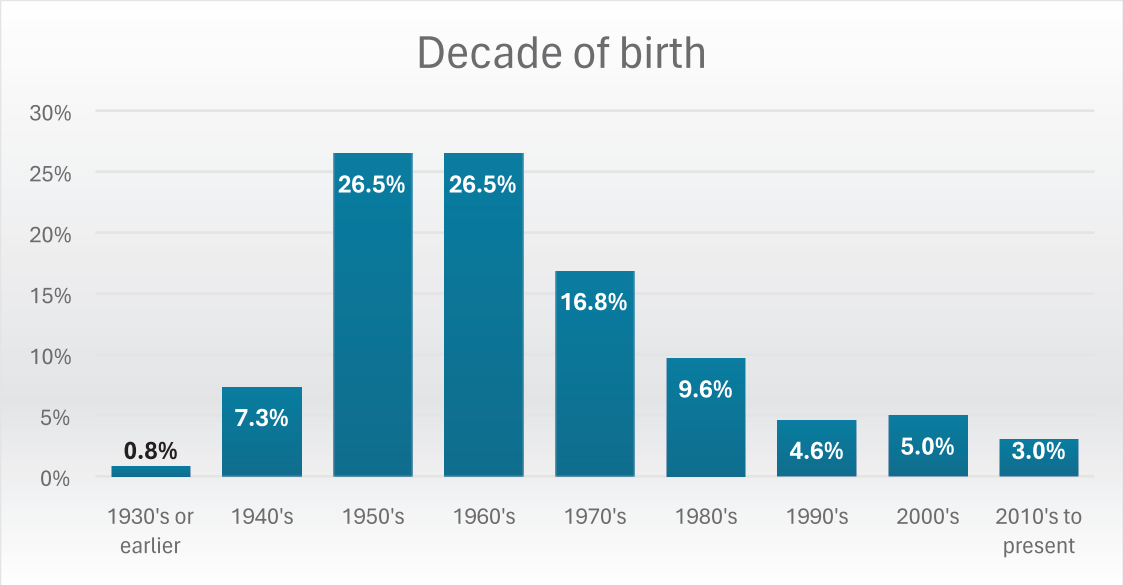
These numbers paint a striking picture: **patients and families are navigating a fractured web of specialists, piecing together care from multiple disciplines in a desperate attempt to keep up with the relentless progression of symptoms.** The effort is immense, the burden overwhelming—and yet the outcomes remain insufficient.

The voices behind these statistics are clear: **families are exhausting the current system, but the system is not exhausting every possibility for them.** What's needed is a shift—from reactive, symptom-focused care to proactive innovation. Clinicians, researchers, and industry partners must come together to identify and test new interventions, repurpose therapies, and ensure patients are not left with a future defined only by decline.

Review of Section 1: About You and Your Diagnosis

S1-3. In what year were you born?

A majority of the survey respondents (53%) were born in the 1950s and 1960s (age group around 55-75). Approximately 1 in 8 respondents are under the age of 40.



S1-4. What is your Sex at Birth?
Females represent approximately 6 in 10 survey responses.

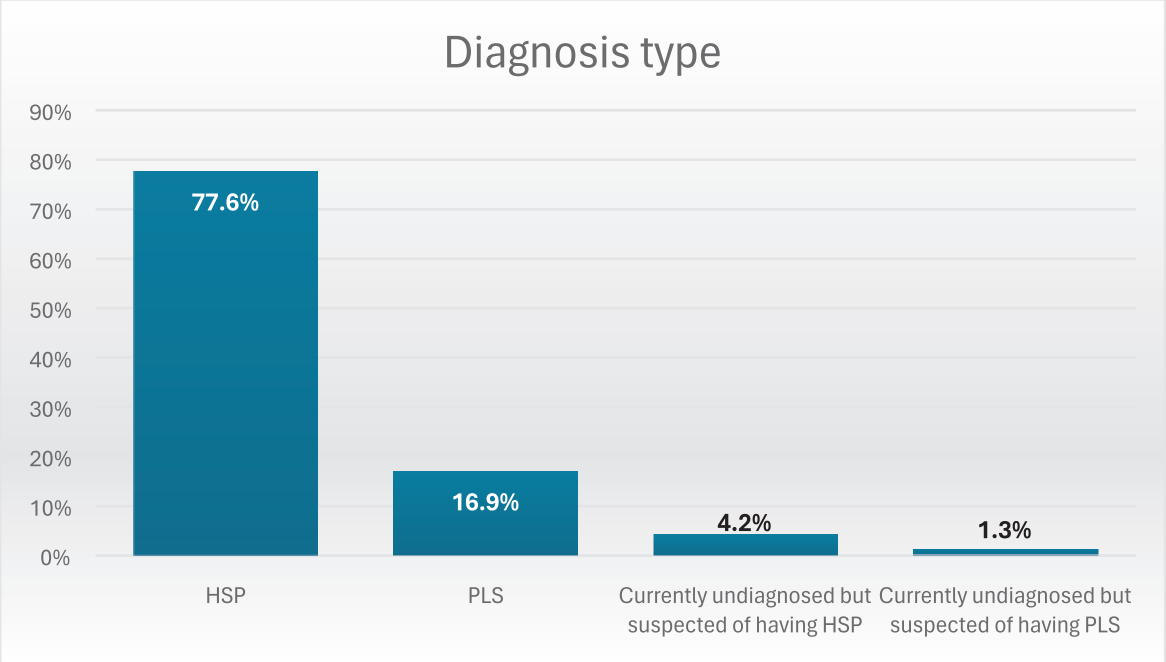
S1-5. Select your marital status
Approximately 6 in 10 survey respondents identify as married.

S1-6. Select your race
Although the survey reached a global audience, the majority of respondents (93.3%) identified as "White or Caucasian." Among respondents from traditionally Hispanic/Latino-majority countries (Spain, Brazil, Argentina, Portugal, and Venezuela), approximately 7 in 10 (69%) identified as "White or Caucasian," while 3 in 10 (29%) identified as Latino or Hispanic.

S1-7. Are you a Veteran or active military service?
Approximately 6% or 44 respondents (about 1 in 20) identified as veterans or active military service members, while 94% were non-veterans. It is important to note that the survey window for SPF members was only 37 days, which limited participation to 770 respondents. The SPF Member Database includes 80 members identified as veterans. This rapid-response requirement likely underrepresents the full veteran population within our community and highlights the need for broader, targeted outreach.

S1-8. Do you currently have health insurance? If so, what type?
10.6% of respondents reported having no insurance, the plurality reported coverage through private health insurance.

S1-9. Have you been diagnosed with Hereditary Spastic Paraplegia (HSP) or Primary Lateral Sclerosis (PLS)?
77.6% of respondents are diagnosed with HSP and 16.9% with PLS. 5.5% are currently undiagnosed. Approximately 8 in 10 respondents are either diagnosed with HSP or are undiagnosed but suspecting HSP. SPF Member Database includes 4,020 people with HSP and 1103 people living with PLS.



S1-10. Do you have another disease along with HSP/PLS?

Around 1 in 4 respondents (26.5%) identify as having another disease or illness along with HSP/PLS. A total number of 290 unique responses were identified. This indicates some respondents identified multiple diseases and chronic illnesses. Responses were provided in free-text form, participants shared a broad variety of input. Given the prevalence of comorbidities and multiple conditions and diseases, medications and subsequent side effects may or may not be directly attributable to treatments regarding HSP/PLS. These discerning factors could not be determined from the survey results indicating that additional research or subsequent surveys may be needed.

General conditions and prevalence

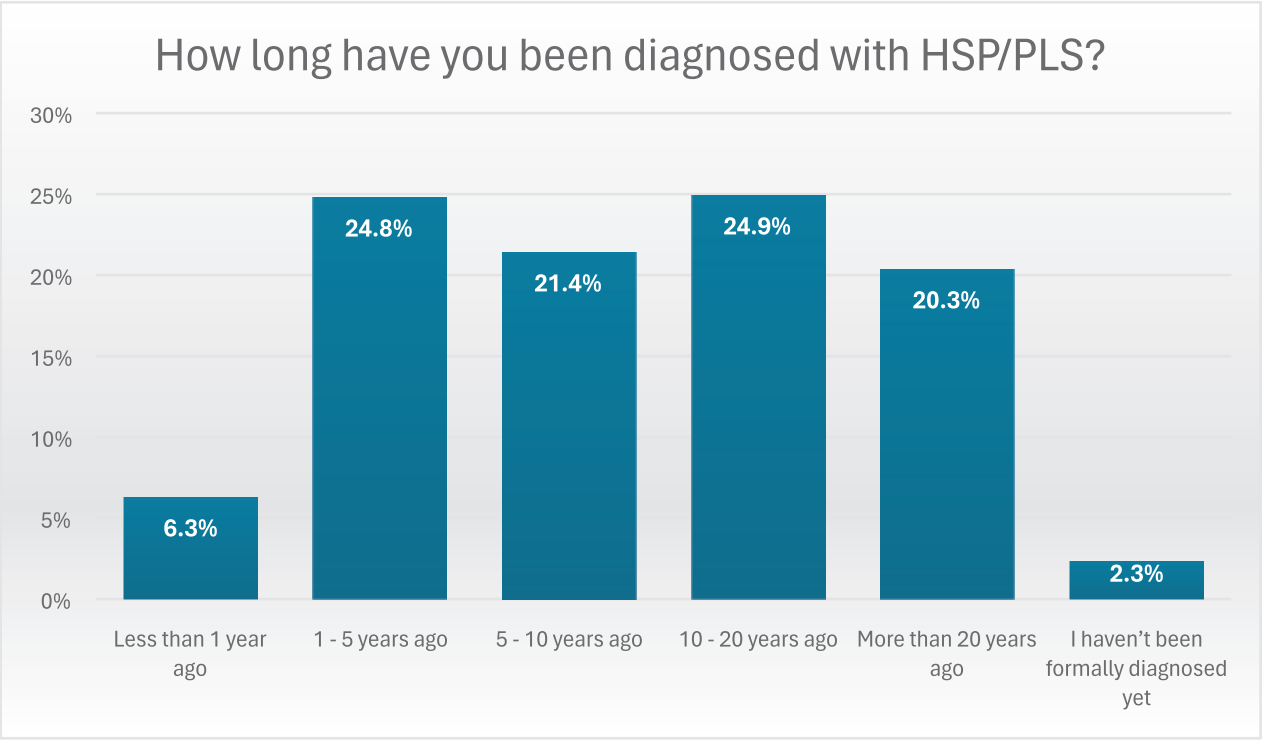
Medical category	Unique Conditions	Total Mentions
Autoimmune & Inflammatory	24	66
Neurological & Motor Function	22	55
Endocrine & Metabolic	13	39
Musculoskeletal & Connective Tissue	11	26
Respiratory	6	24
Cancer & Hematologic	12	23
General Symptoms / Vague Terms	18	22
Gastrointestinal	10	21
Psychiatric & Behavioral	8	17
Genetic & Rare Disorders	9	14
Sensory & Vision	6	11
Developmental & Cognitive	5	10
Urologic & Reproductive	4	7

Most common specific conditions with prevalence

Condition / Disease Mentions	Mentions
Diabetes (all types)	10
Asthma	9
Hypertension	6
Hypothyroidism	5
Fibromyalgia	5
Osteoporosis	5
Ataxia (including SCA18)	5
Epilepsy	4
COPD	4
Rheumatoid Arthritis	4
Crohn’s Disease	4
Ankylosing Spondylitis	4
Hashimoto’s Thyroiditis	4

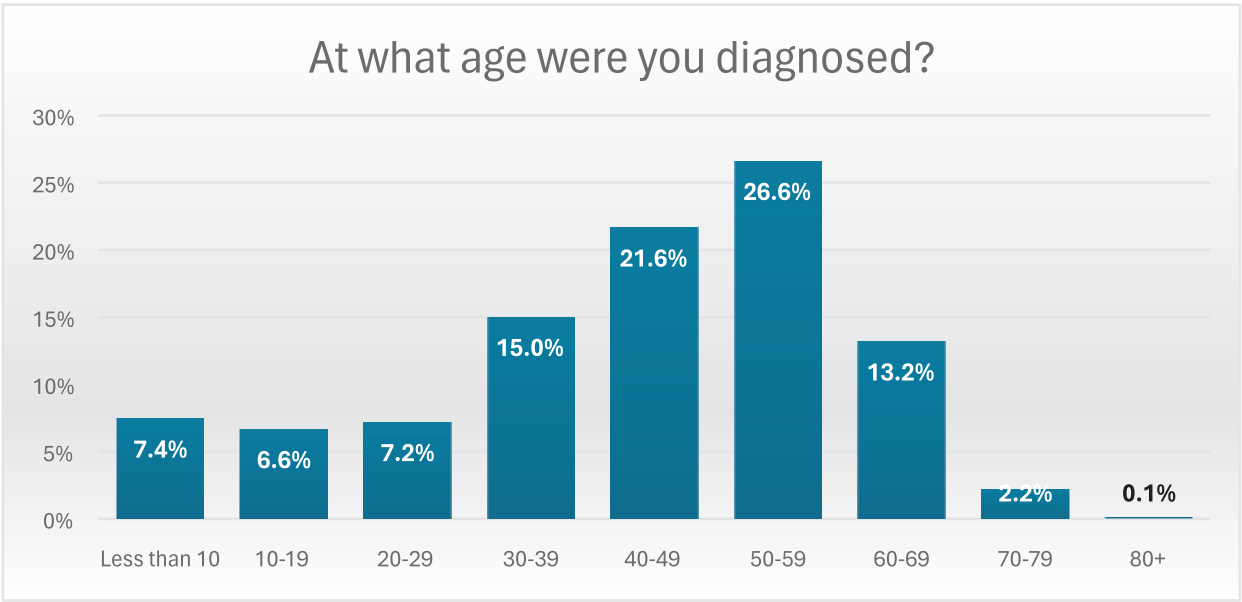
S1-11. How long have you been diagnosed with HSP/PLS?

The survey represents a wide spread of diagnosis timeframes. Only 1 in 20 were diagnosed in the last year and very few respondents (2.3%) do not currently have a formal diagnosis.



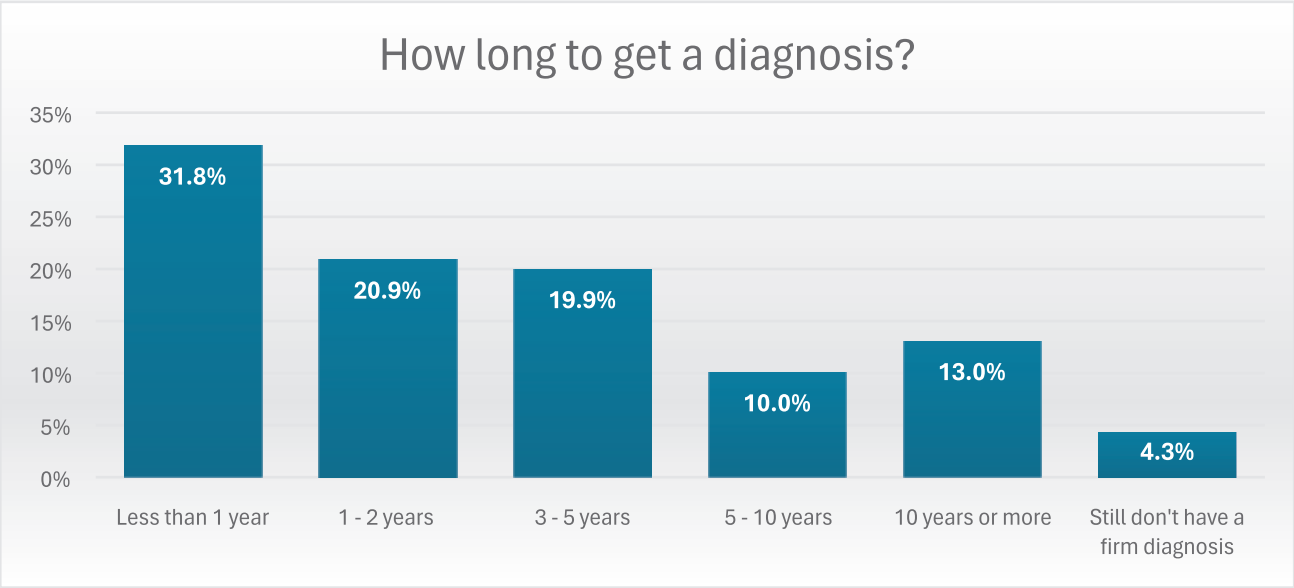
S1-12. What age were you when diagnosed?

Nearly half (48.2%) of the survey responses were diagnosed between 40 and 69 years of age with around 1 in 4 respondents diagnosed in their 50s. Those diagnosed under the age of 30 represent around 1 in 5 (21.2%) respondents.

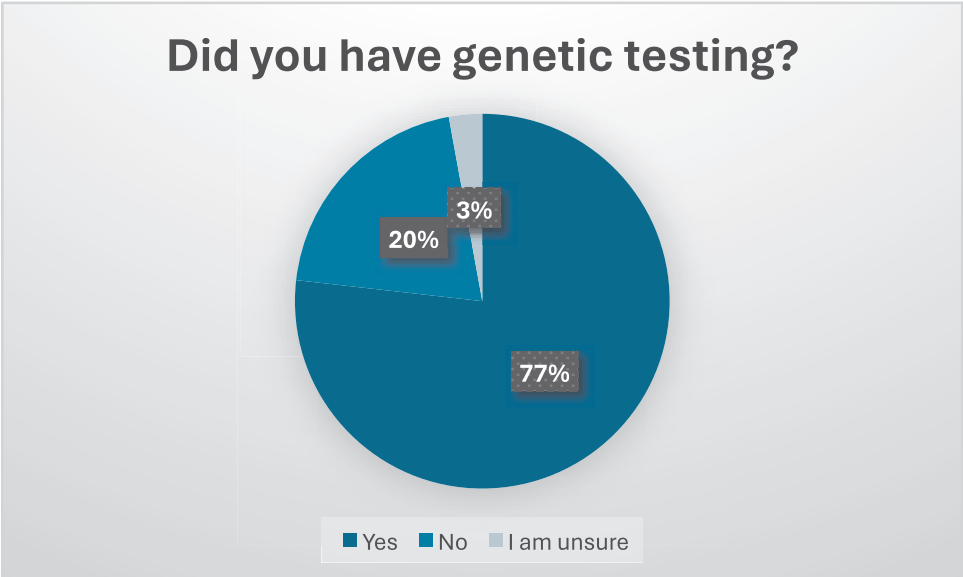


“The journey to diagnosis was horrible. I was dismissed for years.”
“Doctors must treat us with compassion, not disbelief.”- patient

S1-13. How long did it take to get a diagnosis?
A majority of respondents received a diagnosis in less than a year, representing 1 in 3 survey respondents.

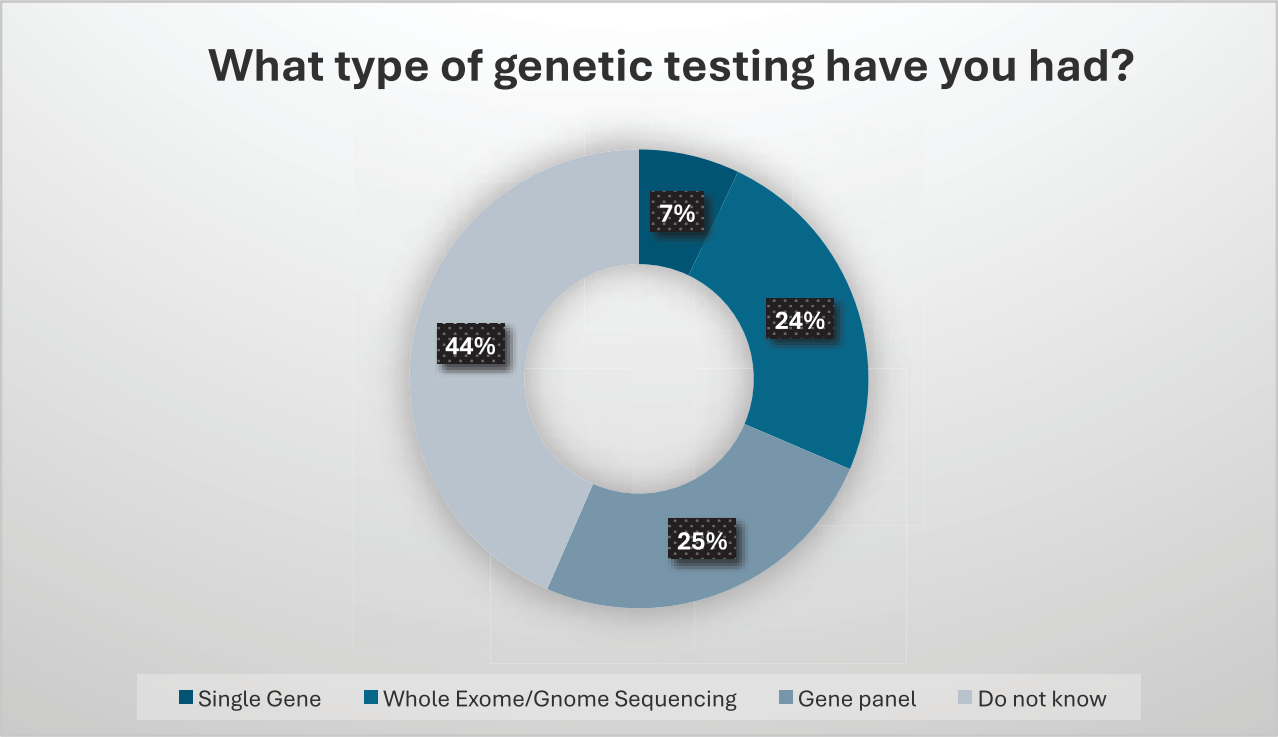


S1-14. Did you have genetic testing?
Most respondents (around 8 in 10) had genetic testing performed.



S1-15. What type of genetic testing have you had?

Most of the 633 respondents (44%) are unfamiliar with the type of genetic testing performed. Of those who are aware, fewer than 1 in 10 had 'single gene' testing performed, while 'whole exome/genome sequencing' and 'gene panel' each equally represent approximately 1 in 4 survey responses.



S1-16. Do you know the company that did the genetic testing?

Only 530 responses answered the question. Below is a breakdown of companies listed by patients.

Company	Responses
Invitae Corp	130
Athena Diagnostics	72
GeneDX	32
MNG Laboratories	10
Mendelics	15

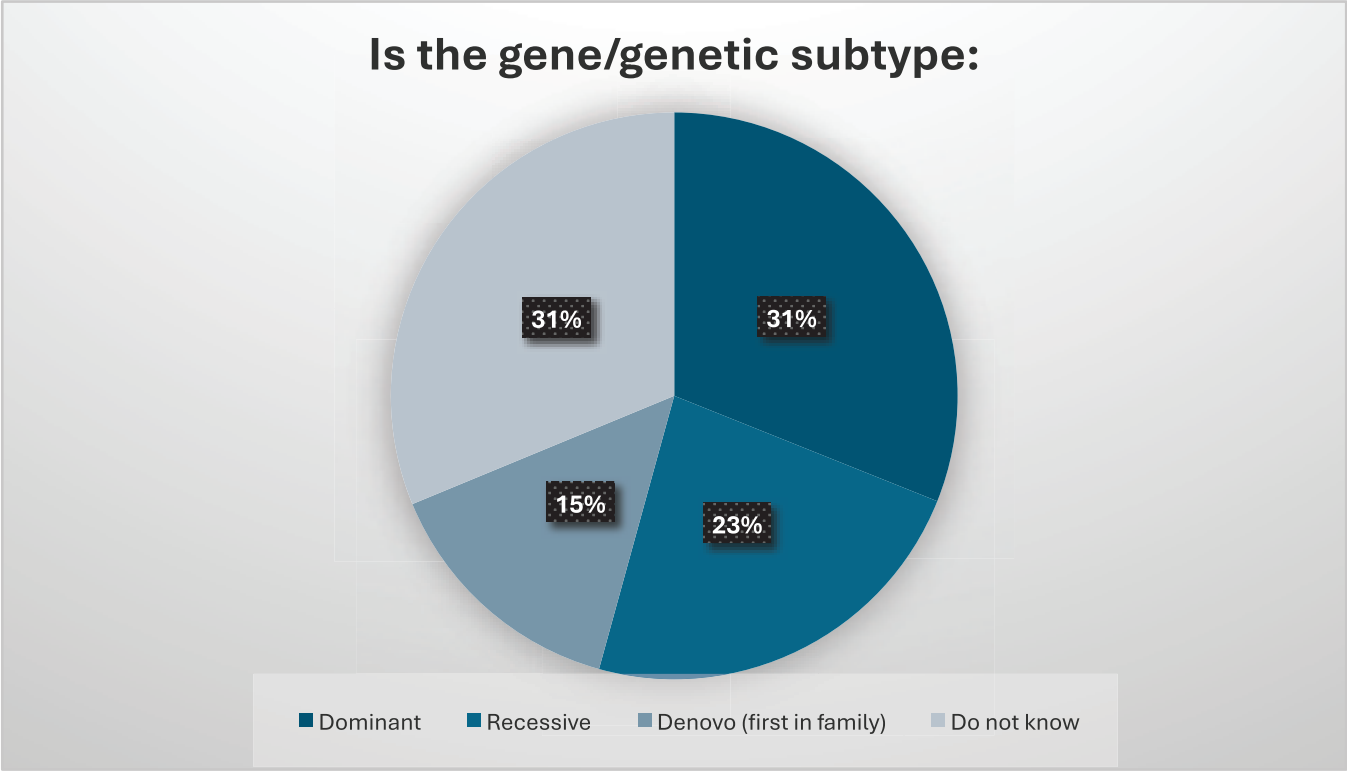
S1-17. If HSP, do you know the gene and/or genetic subtype - e.g. SPG4 (SPAST), SPG3A (ALT1), SPG31 (REEP1), SPG10 (KIF5A), etc.?

The most identified genetic subtypes were SPG4 and SPG7 followed by SPG 11. Many other genetic subtypes were also identified.

Genetic Subtype	Number of responses	SPF Membership
SPG4	202	629
SPG7	102	373
SPG11	29	131
SPG3A	16	75
SPG10	11	49
SPG8	9	48
SPG30	3	37
SPG31	8	36
SPG5A	5	34
SPG6	10	32
SPG15	9	31
SPG5	5	22
SPG76	5	11
SPG9A	4	10
SPG3	2	10
SPG2	1	9
SPG50	1	9
SPG39	1	8
SPG56	1	7
SPG73	5	6
SPG12	1	6
SPG80	1	6
SPG46	2	5
SPG17	1	5
SPG26	1	5
SPG20	1	3
SPG72	1	3
SPG77	2	2
SPG79A	2	2
SPG21	1	2
SPG82	1	2
SPG88	1	2
SPG33	3	1
SPG84	1	1

S1-18. Is the gene / genetic subtype - Dominant, Recessive or Denovo (first in family)?
Nearly a third of 573 respondents do not know the gene or genetic subtype. In terms of those who are aware of the genetic subtype, around 1 in 3 respondents identify the dominant gene, while around 1 in 4 respondents identify the recessive gene type. 1 in 6 respondents identify as Denovo, or first in family.

Figure 8: Genetic testing results.



Review of Section 2: Symptoms and Their Impact

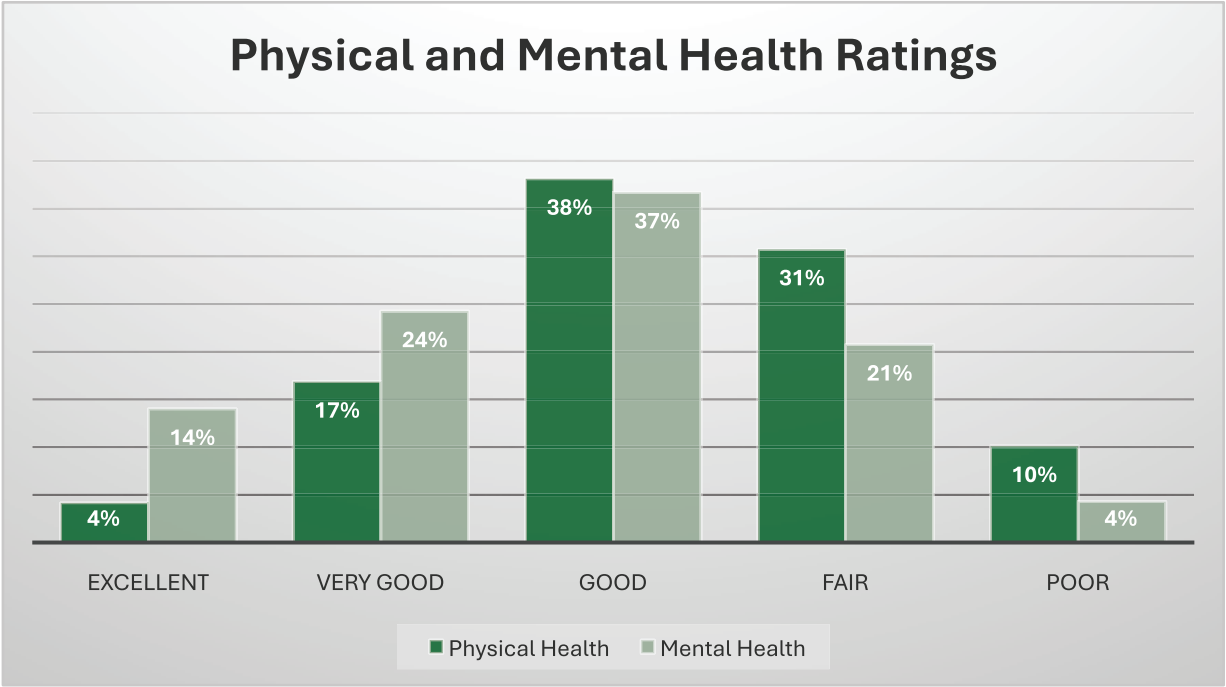
"Like many with HSP, I have great difficulty walking; fatigue and spasms get worse with stress." - patient

"People don't understand how much effort it takes to walk; by the time I get things done I'm drenched in sweat." - patient

"My legs are very weak and continue to get worse; balance issues are constant." - patient

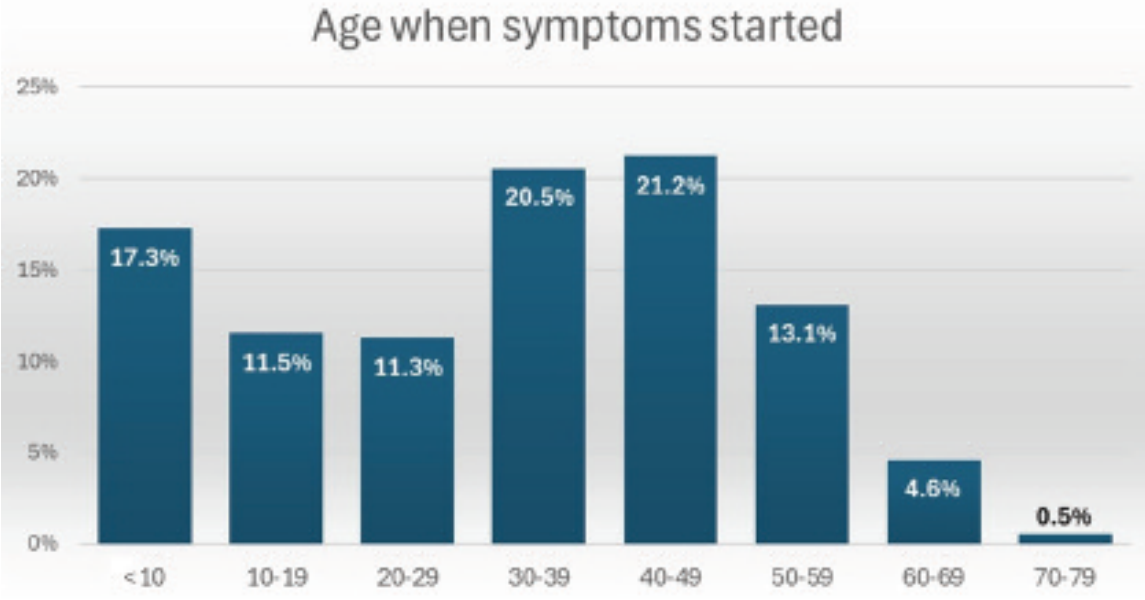
"Falls are terrifying; I plan routes around railings and seating." - patient

S2-1. How would you rate your physical health? is merged with S2-2. How would you rate your mental health?
Mental health ratings show somewhat of a mirror to physical health ratings. In both responses, the middle category "good" represents nearly 4 in 10 respondents, however, in categories assessed better than "good" mental health is represented in nearly double the number of respondents as assessed worse than "good" (295 versus 193 respondents). The opposite is true, a flip across the middle "good" axis when it pertains to physical health ratings (315 vs 162 respondents).



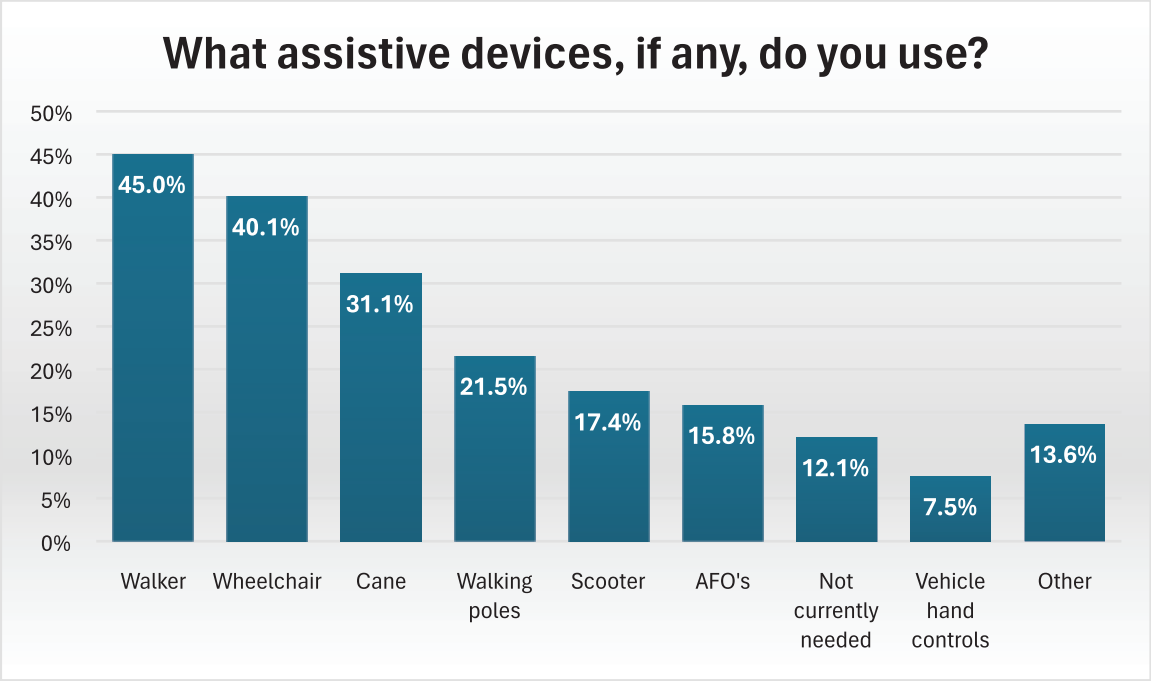
S2-3. How old were you when symptoms started?

Most respondents (41.4%) were between the ages of 30 and 49 when symptoms started. Nearly 1 in 5 respondents experienced symptoms before age 10, and more than 1 in 4 experienced symptoms before the age of 20. Data shows that we now have fewer than two years latency between symptom to diagnosis among those with HSP/PLS. Fortunately, it looks like the time from symptoms to diagnosis has decreased rather drastically in recent decades.



S2-4. What assistive devices, if any, do you use?

87.9% of the respondents use one or more assistive devices.

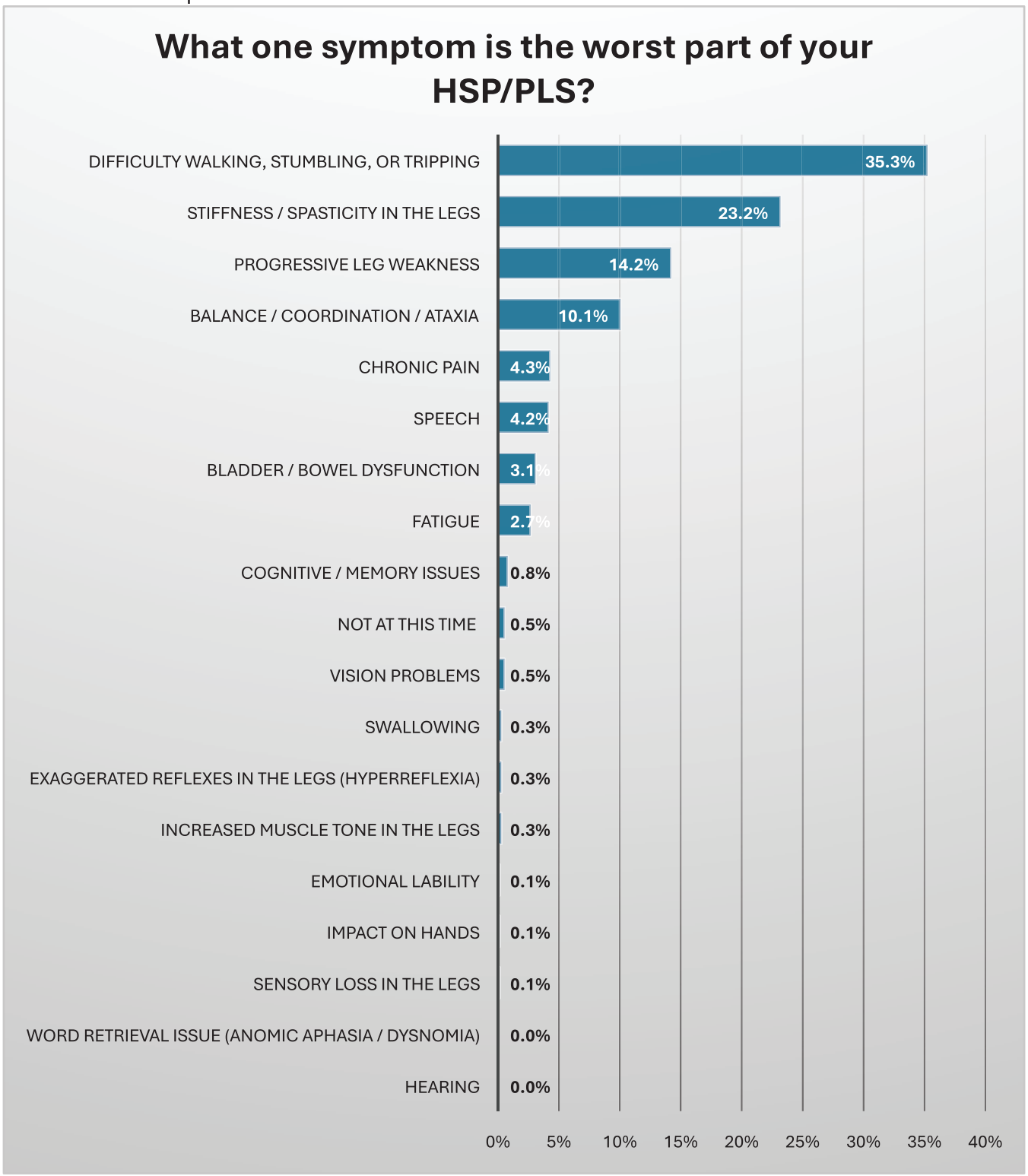


S2-5. What symptoms have you experienced as part of your HSP/PLS?

Nearly all respondents (94.2%) identified “difficulty walking, stumbling, or tripping” as a symptom experienced with HSP/PLS. Stiffness or spasticity in the legs was also a symptom in more than 9 of 10 respondents.

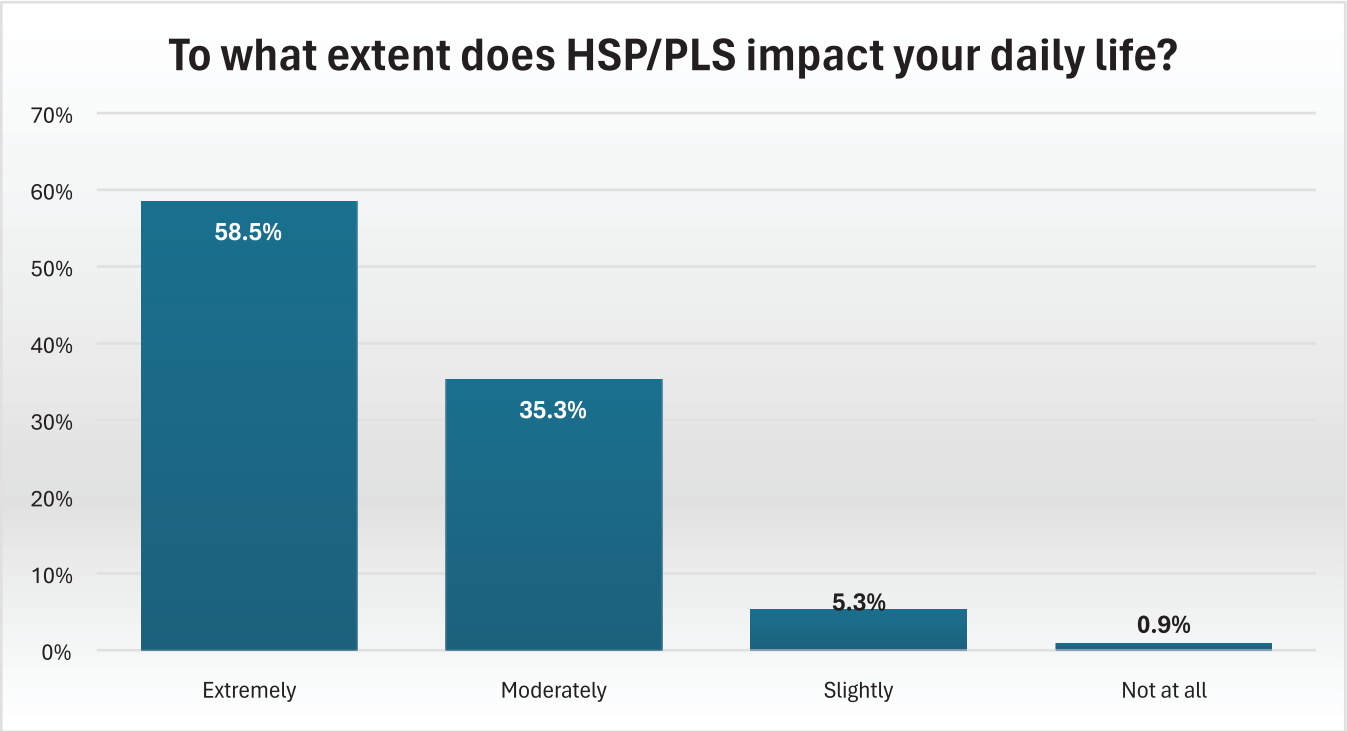
S2-6. What one symptom is the worst part of your HSP/PLS?

More than 1 in 3 of respondents indicated the worst part of HSP/PLS is difficulty walking, followed by around 1 in 4 respondents identifying stiffness or spasticity in legs. Progressive leg weakness was identified as the worst symptom for 1 in 7 respondents, while 1 in every 10 respondents referenced balance/coordination issues. All other symptoms combined represented around 17% of responses but with none receiving more than 5% of the total amount of responses.



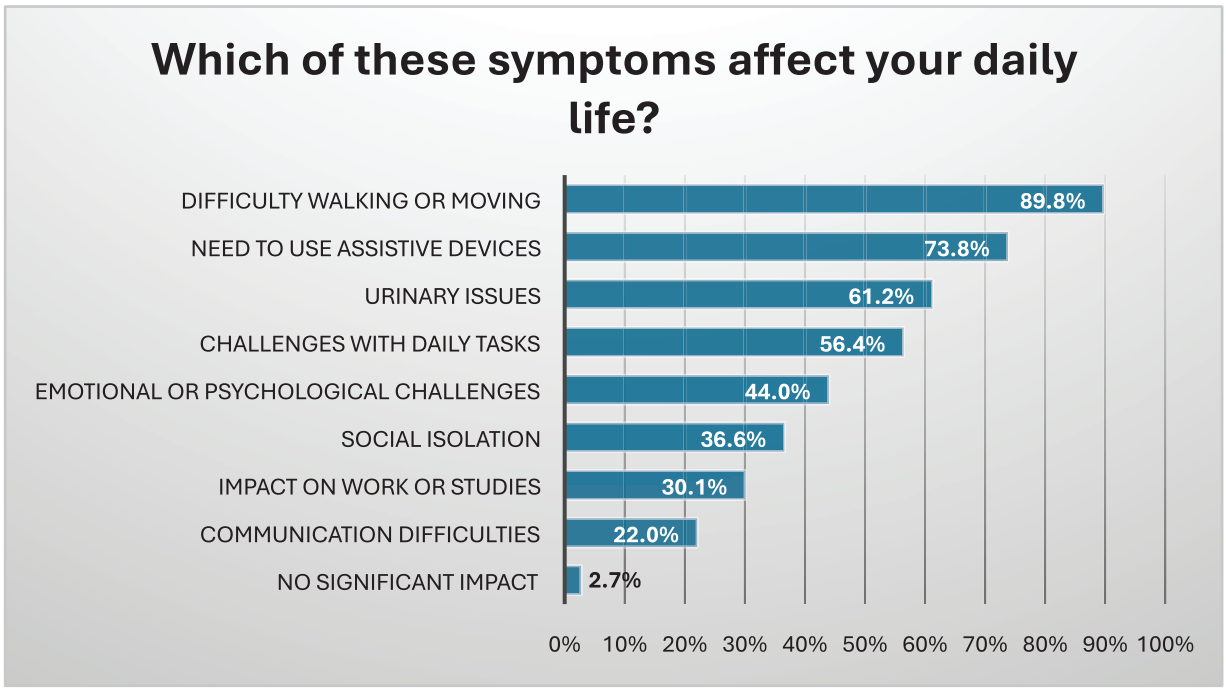
S2-7. To what extent does HSP/PLS impact your daily life?

Nearly 6 in 10 respondents indicate that HSP/PLS extremely impacts their daily life. Only around 1 in 20 report they are slightly impacted or not at all.



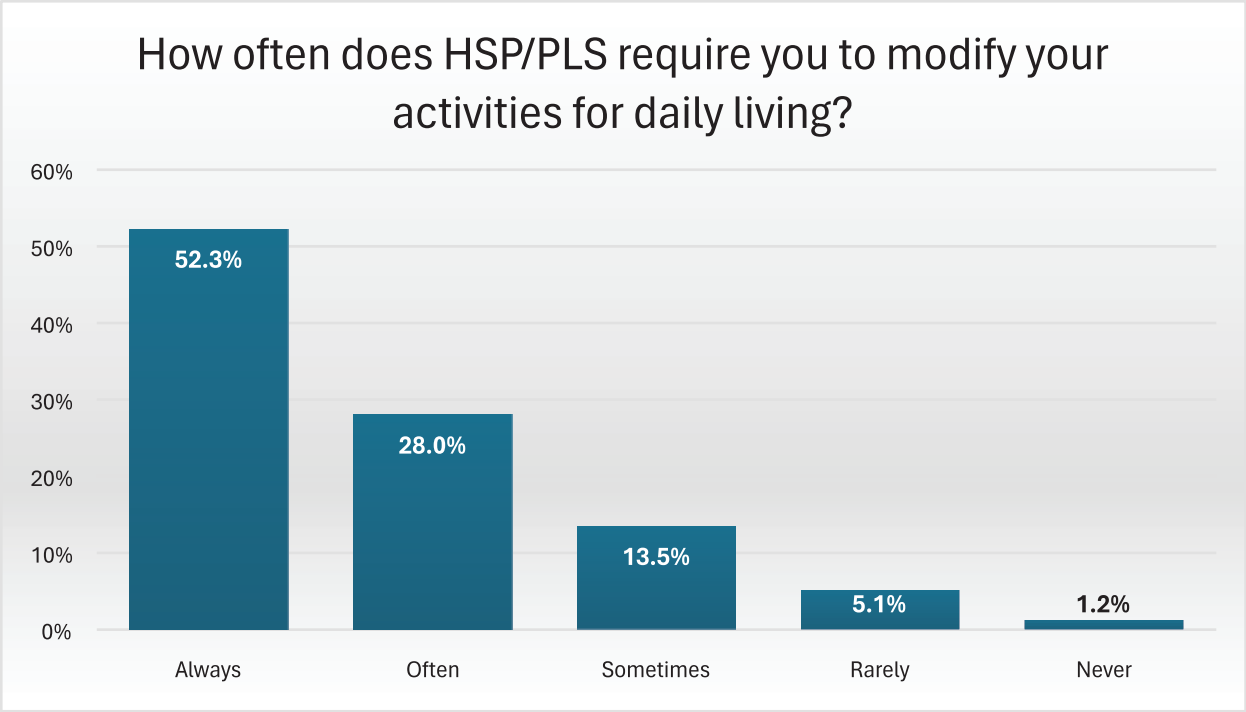
S2-8. Which of these symptoms affect your daily life?

Around 9 in 10 respondents cite difficulty walking or moving as a symptom affecting daily life, while 3 in 4 of the respondents cite the need to use assistive devices. 6 in 10 express urinary issues, and more than half of respondents expressed challenges with daily tasks such as dressing, and showering.



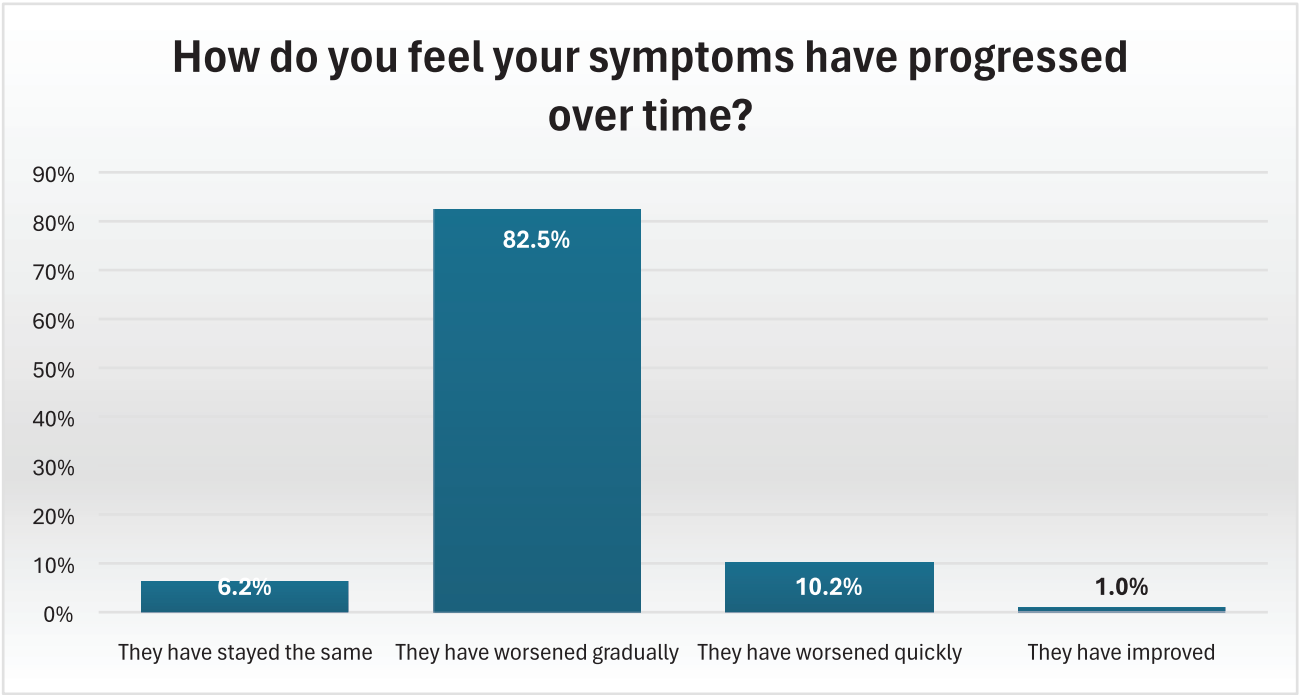
S2-9. How often does HSP/PLS require you to modify your activities for daily living?

More than 4 in 5 survey respondents express that HSP/PLS requires they modify their activities for daily living "always" or "often". Nearly all (93.8%) find that their activities are modified at least "sometimes".

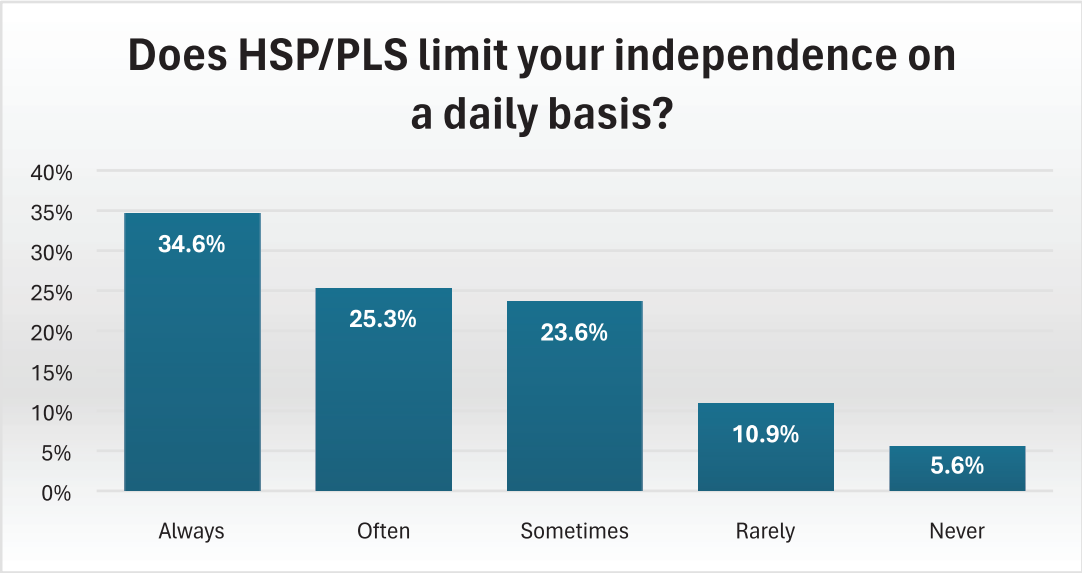


S2-10. How do you feel your symptoms have progressed over time

Most respondents (82.5%) find their symptoms have gradually gotten worse, while 1 in 10 have found their symptoms to have worsened quickly. Only around 1 in 20 respondents find their symptoms have stayed the same or improved.



S2-11. Does HSP/PLS limit your independence on a daily basis?
Around one third (34.6%) of respondents find HSP/PLS to limit their independence daily. Most (83.5%) respondents find their independence to be limited at least 'sometimes'.



Review of Section 3: Treatment and Management

"Please, more research and a possible cure. Seeing our children suffer is unbearable." – parent

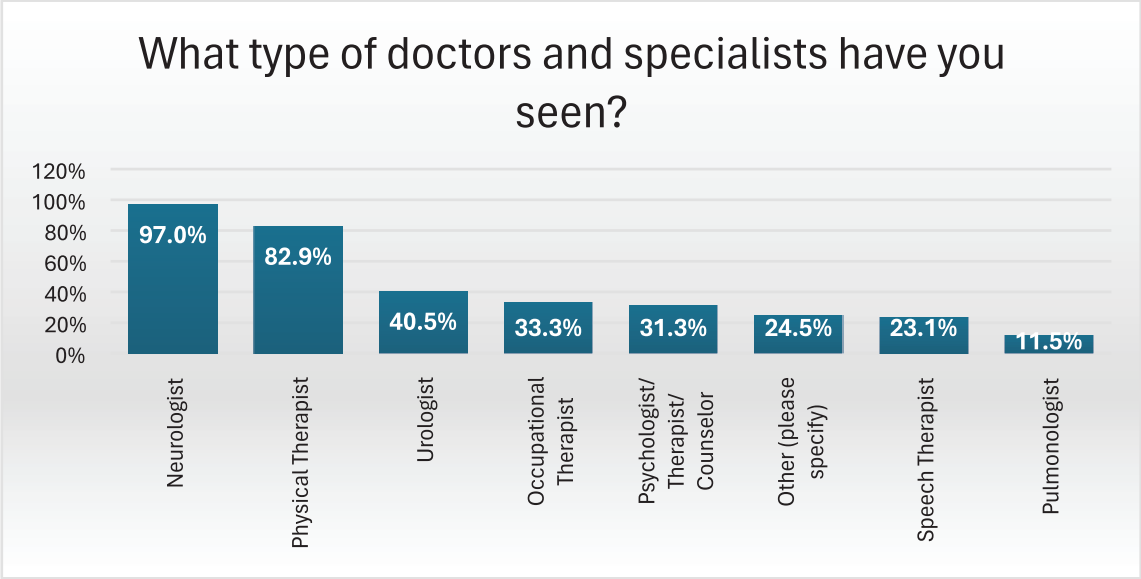
"Our big concern presently is finding a group home setting for my 29 year old son to move into given his father has passed away and his mother, at 70 years old, is caring for him by herself. The need for housing for the intellectually, developmentally disabled is a HUGE NEED in our country because they will be the first to go homeless without family to care for them." - parent

S3-1. Is being knowledgeable about HSP/PLS important to you?
Nearly all survey respondents (94.4%) felt knowledge of HSP/PLS was important to them.

S3-2. How knowledgeable do you feel you are about HSP/PLS and its origin, symptoms, effects on the body, treatment, and care?
A majority (55%) of respondents are comfortable with their current level of knowledge; however, it is indeterminate the nature of that knowledge beyond a wholistic understanding of HSP/PLS.

S3-3. What type of doctors and specialists have you seen?

Nearly every respondent (97%) has seen a neurologist for their symptoms, and most (82.9%) have also seen physical therapists. Other relevant conditions are also referred to specialists; however, fewer than half of respondents report any one type of specialist.



S3-3a. If you answered OTHER, please specify.

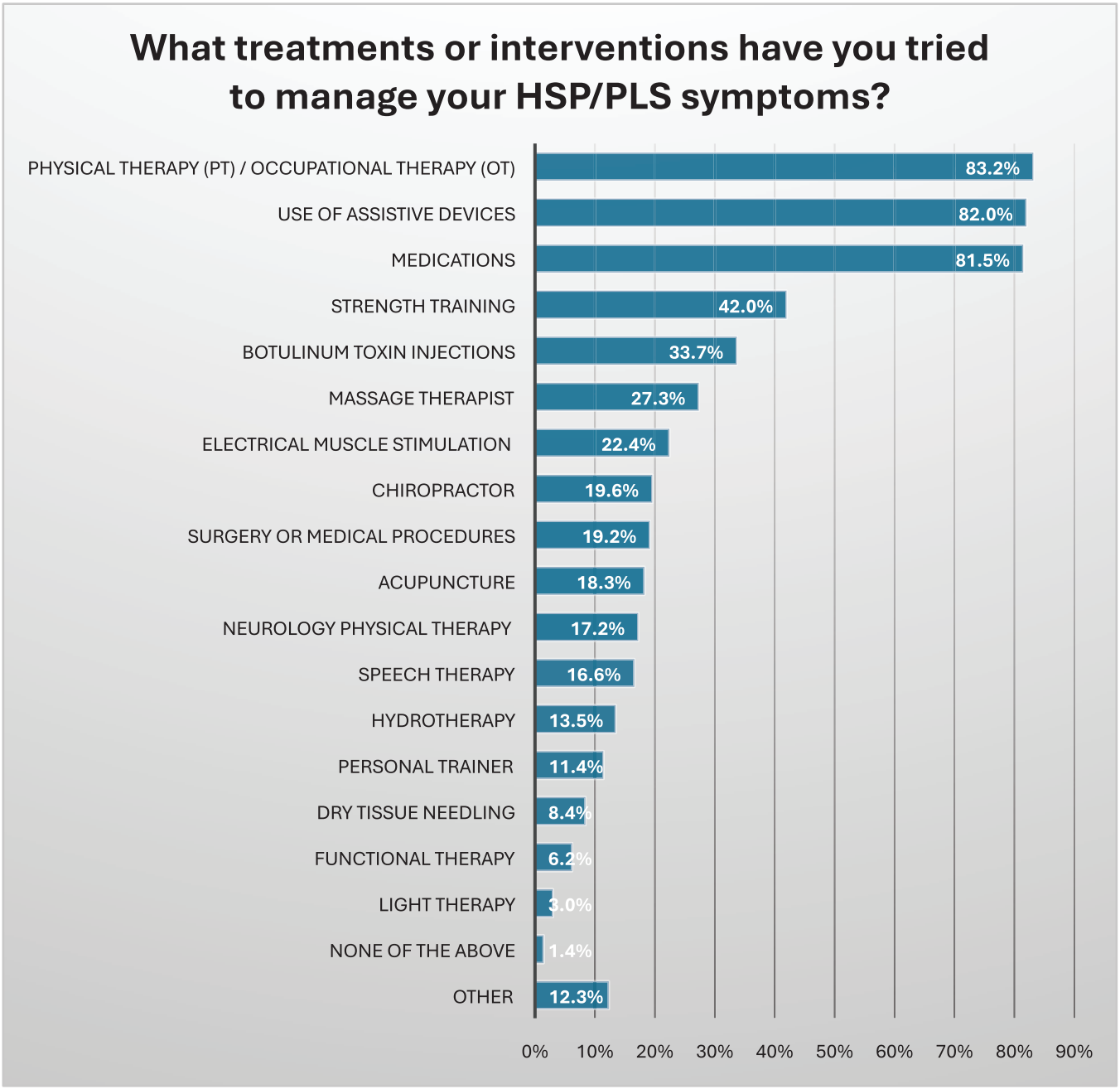
Many respondents identified other doctors and specialists they see, many of whom identify more than one. Overall, 349 specialists were identified. The chart below indicates the specialty domain of those mentioned including the count of respondent mentions and examples of the types of specialists that correspond with the particular specialty domain.

Specialty Domain	Count	Notes
Physical Medicine & Rehabilitation	52	Physiatrists, PM&R, MPR, rehab clinics, neuro rehab
Orthopedics & Musculoskeletal	34	Orthopedic surgeons, consultants, pediatric orthopedists
Neurology & Neurosurgery	28	Neurologists, neurosurgeons, neurogeneticists, neuro PTs
Chiropractic & Manual Therapy	26	Chiropractors, massage therapists, Alexander Technique
Cardiology & Vascular	22	Cardiologists, vascular surgeons, stents
Gastroenterology & Digestive Health	18	Gastroenterologists, neurogastroenterologists, bowel surgeons
Pain Management	17	Pain doctors, pain clinics, baclofen pump specialists
Psychiatry & Psychology	14	Psychiatrists, psychoanalysts, counselors, electro-psychiatrists
Genetics & Rare Disease	13	Geneticists, gene specialists, HSP testing
ENT & Audiology	13	ENTs, otologists, audiologists
Physical Therapy & Movement	13	Physiotherapists, kinesiologists, exercise physiologists,
Ophthalmology & Vision	12	Ophthalmologists, neuro-ophthalmologists, orthoptists
General & Internal Medicine	12	PCPs, internists, family doctors, regular MDs
Clinics & Multidisciplinary Teams	12	ALS, spasticity, sleep, rehab, ReACH team, functional rehab
Pediatrics	11	Pediatricians, pediatric ophthalmologists, pediatric geneticists
Alternative & Functional Medicine	11	Naturopaths, functional medicine, holistic doctors
Surgical Specialists	11	Surgeons for back, shoulder, bowel, pump replacement
Social & Support Services	7	Social workers, hospice teams, Reach referrals

Urology & Pelvic Health	6	Urologists, urogynecologists, pelvic floor specialists
Respiratory & Pulmonology	6	Pulmonologists, respiratory therapists, asthma/immunology
Nutrition & Wellness	6	Nutritionists, nutrologists
Other Modalities	5	Yoga, functional trainers, movement specialists

S3-4. What treatments or interventions have you tried to manage your HSP/PLS symptoms?

The most common items for symptom management are physical therapy, use of assistive devices, and medications—each of which are identified by more than 8 in 10 of the respondents in the survey.



S3-4a. If you answered OTHER, please specify.

Free response inputs for this question yielded 96 verifiable responses. Overall the most common category of treatment was in the 'physical and movement therapy' section, representing 39 unique responses. The table below offers more detail and examples of treatments in each treatment category.

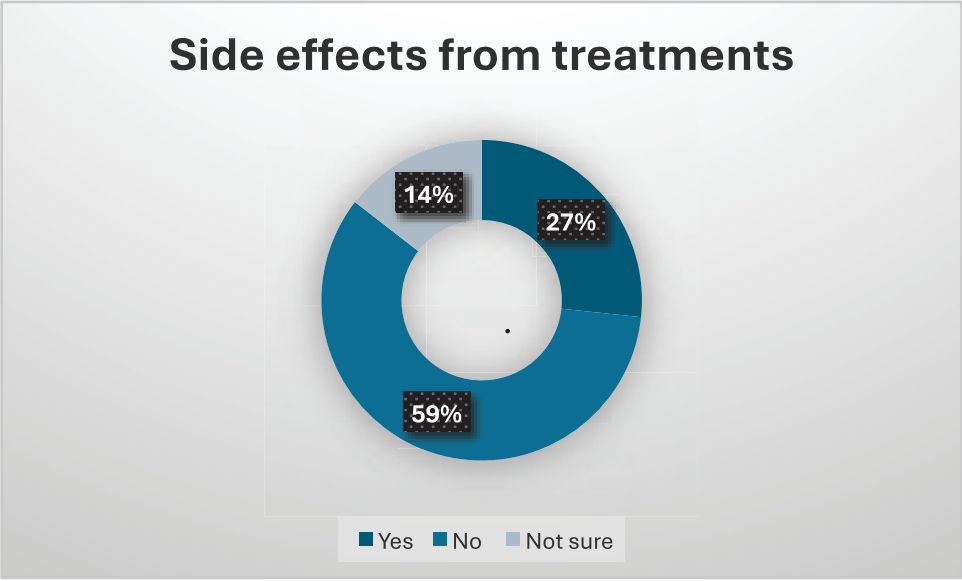
Treatment Category	Exact Count	Notes
Physical & Movement Therapy	39	Yoga, Pilates, Feldenkrais, swimming, stretching, sports
Alternative & Complementary Therapies	14	Reiki, cupping, cannabis, craniosacral, hyperbaric
Medication & Injections	13	Baclofen, Lyrica, Naproxen, Tramadol, Botox, Dalfampridine
Medical Devices & Equipment	12	Baclofen pump, AFOs, TENS, vibration plate, Walkaide
Nutrition & Wellness	5	Clean diet, supplements, NAD+, sauna
Surgical & Procedural Interventions	3	Baclofen pump surgery, neuro stimulator
Chiropractic & Manual Therapy	3	OMT, upper cervical care, osteopathy
Psychosocial & Support Services	2	CBT, meditation
Regenerative Therapy	2	Stem cell infusion, mesenchymal stem cells
Sleep & Rest Support	2	Rest, NIV
Diagnostic & Monitoring	1	MRI, angiography

S3-5. How effective have these treatments been in improving your symptoms or quality of life?

While a particular treatment was not able to be isolated in this question, nor was it determinate if the answer referred to a singular treatment or the results from multiple, most respondents found their treatments to be 'somewhat effective" (65.4%).

S3-6. Have you experienced any side effects from your treatment(s)?

Around 1 in 4 respondents report side effects from treatments.



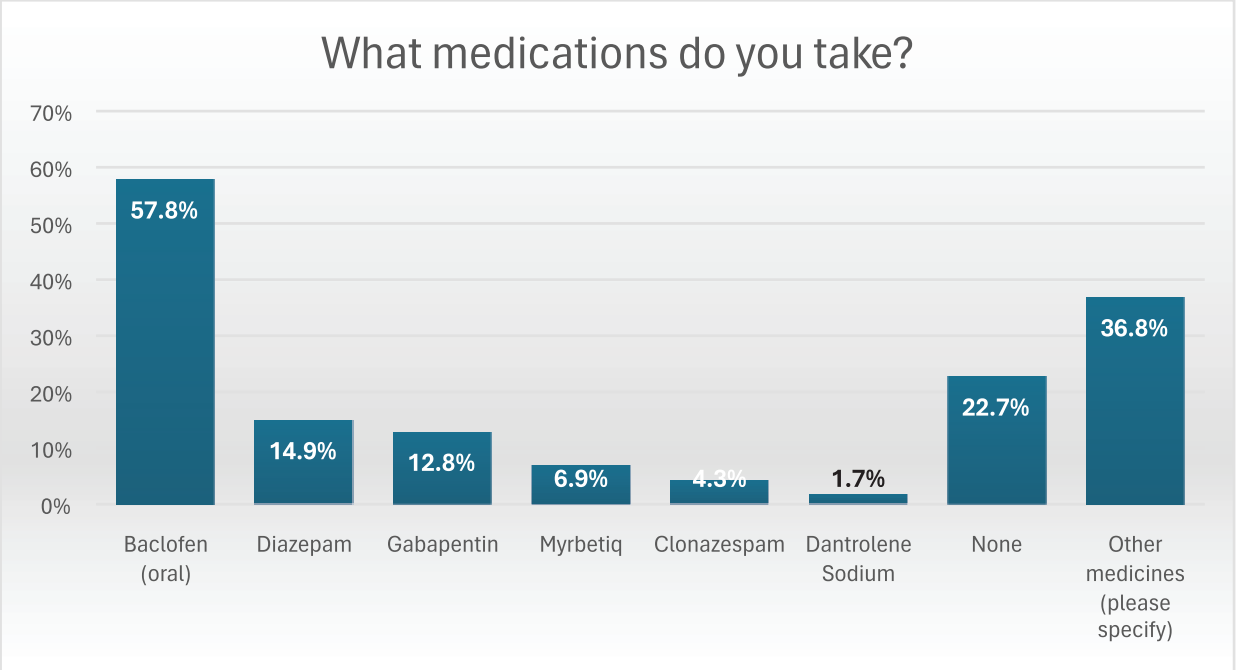
S3-6a. If you answered YES, please specify.

A total of 200 respondents answered this question and provided free response answers that spoke to side effects. Many of the side effects mentioned were unable to be tied to a particular treatment; however, some were specifically enumerated. The most common side effect category mentioned was fatigue/tiredness (87 responses) followed by drowsiness (32 responses) and pain (28 responses). Within these responses, specific reference between medication/treatment and side effects were also found. While some of these conclusions may be assumptive from respondents, the results still show the perceived connection between treatment and side effects. The most common connections drawn by respondents are those side effects associated with baclofen (38 mentions) and Botox (17 mentions). Several side effects were mentioned within each medication/treatment category.

Symptom Category	Frequency
Fatigue / Tiredness	87
Drowsiness / Sedation	34
Pain (General & Therapy-Induced)	28
Muscle Weakness	21
Brain Fog / Cognitive Decline	19
Other / Unclassified	12
Dry Mouth / Dehydration	11
Spasticity / Tightness	10

S3-7. What medications do you take?

Baclofen is the most common medication taken among survey respondents, encompassing nearly 6 in 10 of all respondents.



The following chart reports medications by respondents that correspond broadly to symptom management by HSP/PLS patients.

Medication Name	Drug Class	Treatment Purpose
Amitriptyline	Tricyclic Antidepressant	Depression, nerve pain, sleep
Ampyra (Dalfampridine)	Potassium Channel Blocker	Walking improvement in MS
Carbidopa-Levodopa	Dopaminergic Agent	Parkinson's disease
Clobazam	Benzodiazepine	Seizures, anxiety
Cyclobenzaprine	Muscle Relaxant	Muscle spasms
Dalfampridine	Potassium Channel Blocker	Walking improvement in MS
Duloxetine	SNRI	Depression, fibromyalgia, nerve pain
Gemtesa (Mirabegron family)	Beta-3 Agonist	Overactive bladder
Keppra (Levetiracetam)	Anticonvulsant	Seizures
Lamictal (Lamotrigine)	Anticonvulsant	Seizures, bipolar disorder
Lamotrigine	Anticonvulsant	Seizures, bipolar disorder
Nuedexta	Neuropsychiatric Agent	Pseudobulbar affect
Oxybutynin	Anticholinergic	Overactive bladder
Riluzole	Glutamate Inhibitor	ALS
Ropinirole	Dopamine Agonist	Parkinson's, restless legs
Tamsulosin	Alpha Blocker	Urinary retention, BPH

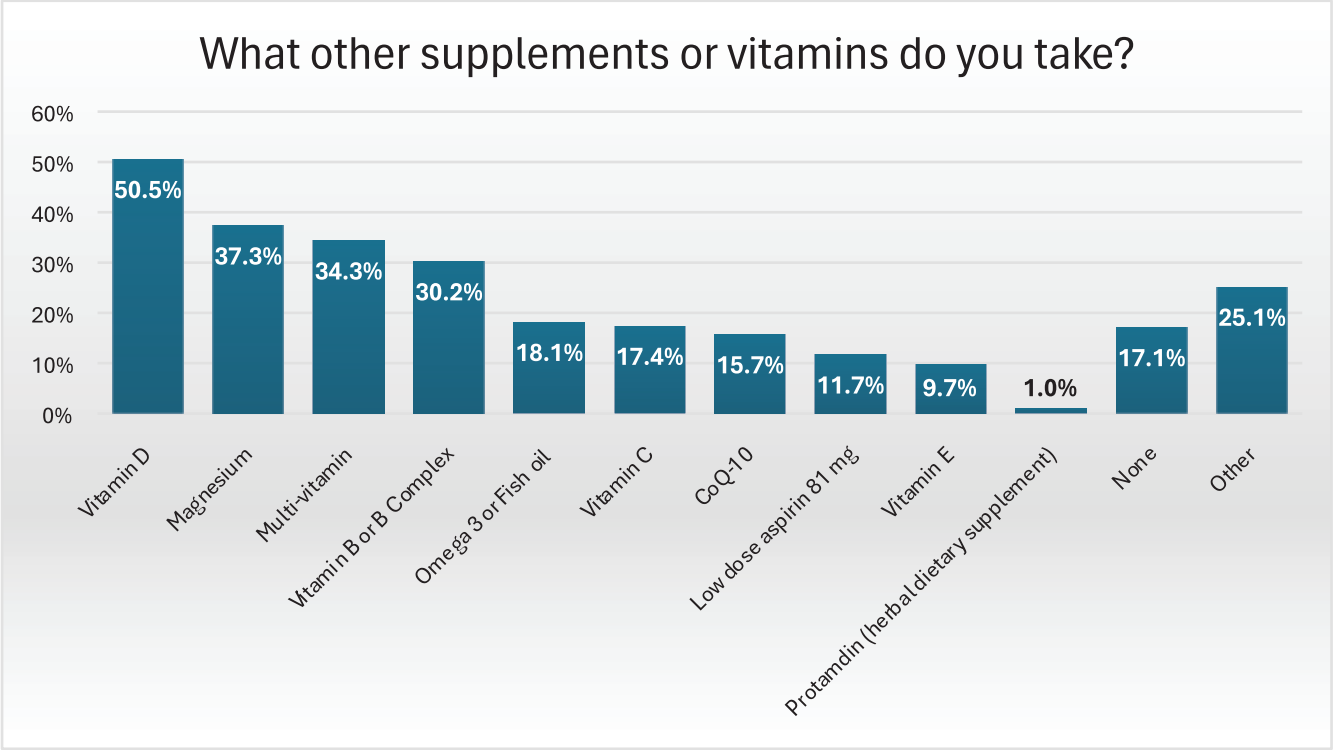
S3-7a. If you answered OTHER, please specify.

Among 308 respondents reporting medication use, the most cited treatment purposes were for depression (90 respondents) and anxiety (60 respondents), reflecting management of secondary conditions. The predominant therapeutic category for these treatments was antidepressants.

Therapeutic Category	Frequency Count
Antidepressants	90
Neurological / Seizures	60
Pain Management	50
Bladder / Urological	40
Cardiovascular	30
Neurological / Parkinson's	20
Gastrointestinal	10
Supplements / Nutritional	10
Sleep / Sedatives	10
Neurological / MS / ALS	10

S3-8. What other supplements or vitamins do you take?

Vitamin D is the most common supplement/vitamin used by respondents, with over half of respondents indicating they take as part of their health plan. Around a third of respondents also report using magnesium or multi-vitamins or vitamin b variants.



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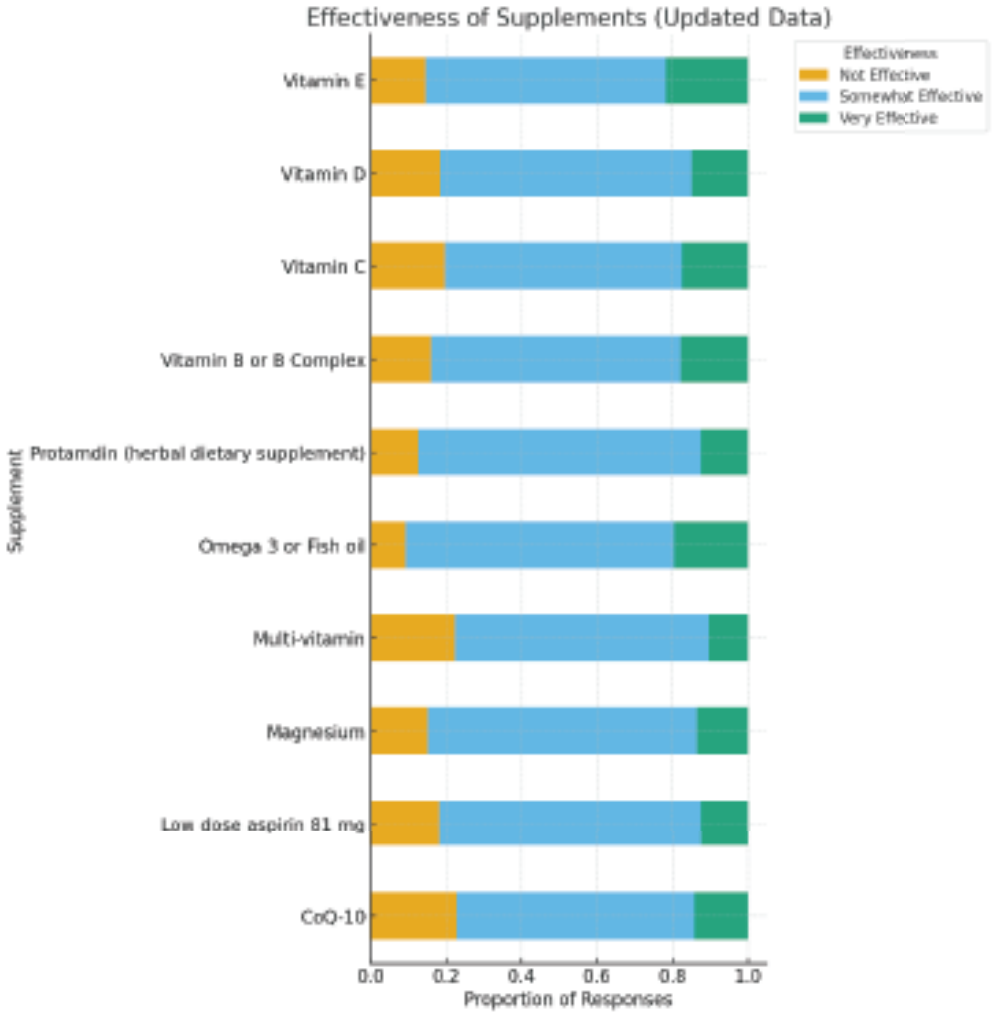
S3-8a. If you answered OTHER, please specify.

A total of 206 respondents answered this question, leading to 277 total verified supplements and vitamins. Calcium was the most common response followed by turmeric, B12, and Iron. The table lists supplements that were noted including functional category, primary purpose, and frequency counts.

Standardized Name	Frequency Count	Functional Category	Primary Health Purpose
Calcium	42	Bone Health	Osteoporosis, bone density
Turmeric	18	Anti-inflammatory	Joint pain, inflammation
B12	14	Neurological / Energy	Energy, nerve function
Iron	13	Hematologic	Anemia, iron deficiency
Melatonin	12	Sleep Aid	Insomnia, circadian rhythm
Zinc	11	Immune Support	Immunity, wound healing
Creatine	10	Muscle Support	Muscle strength, performance

S3-9. How effective have these medications/supplements/vitamins been in improving your symptoms or quality of life?
The following results are experimental and statistically derived. They are not direct responses from the survey and should not be interpreted as accurate representations of survey data. Rather, they provide potential associations that may help inform future survey research.



S3-10. Do you use medical marijuana and what type?
While the majority of respondents (86%) report not using medical marijuana, 14% of patients with HSP/PLS have incorporated it into their care regimen. Those who do report using medical marijuana often seek symptom relief for spasticity, pain, or sleep disturbances. This highlights an area where patients are exploring alternative or complementary therapies, underscoring the need for further research to evaluate potential benefits, safety, and guidance for clinical use in the HSP/PLS community.

S3-11. Do you have trouble sleeping?
Around half of all respondents have trouble sleeping.

S3-12. Do you take anything to help you sleep?
Around 2 in 3 respondents do not take anything to help them sleep.

S3-13. How much sleep do you get a day/night?
Nearly 8 in 10 respondents receive between 4 and 8 hours of sleep. Nearly half of respondents get between 7 and 8 hours of sleep. Those who have no trouble sleeping and do not take medication receive approximately 90 more minutes of sleep than those who have difficulty. This is statistically significant. There is no statistical significance in average hours of sleep for those who claim trouble sleeping and take or do not take medicine.

Trouble Sleeping?	Sleep aid	Count	Avg Hours of Sleep
No	No	313	7.46 hours
Yes	No	143	6.03 hours
No	Yes	57	7.34 hours
Yes	Yes	188	6.18 hours

Review of Section 4: Support and Resources

"Living with PLS has been challenging, but I learned a lot about myself and about life. Even though PLS has robbed me of my ability to walk and talk, I have learned to be more grateful for the little things and to cherish every moment. I have also learned that it is possible to live a full and meaningful life even with a chronic illness." - patient

S4-1. What kinds of support have you received or used to manage your HSP/PLS?
Nearly 9 in 10 respondents have used healthcare professions to manage their HSP/PLS, and almost 2 in 3 have relied on family or social support.

S4-2. Do you currently use and benefit from the following health care resources or services to help manage life with HSP/PLS?
Nearly half of respondents utilize and benefit from medical or mobility assistive devices.

S4-3. What additional resources or support would be helpful to you?
Around 2 in 3 respondents seek more information on patient treatment options, and nearly half of respondents (43.5%) are interested in additional resources in social support groups.

S4-4. Thinking about all the different things you do to manage living with HSP/PLS, what is your best estimate of the time you spend during a typical week doing the following activities/tasks?
Survey respondents reported that managing life with HSP/PLS is not limited to living with physical symptoms—it also requires substantial time and energy dedicated to care coordination. On average, patients spend nearly 9 hours per week on disease-related tasks. The largest share of this time is devoted to monitoring symptoms and disease progression (2.5 hours/week), followed by scheduling medical visits or services (1.6 hours/week), and participating in therapies or treatments (1.0 hour/week).

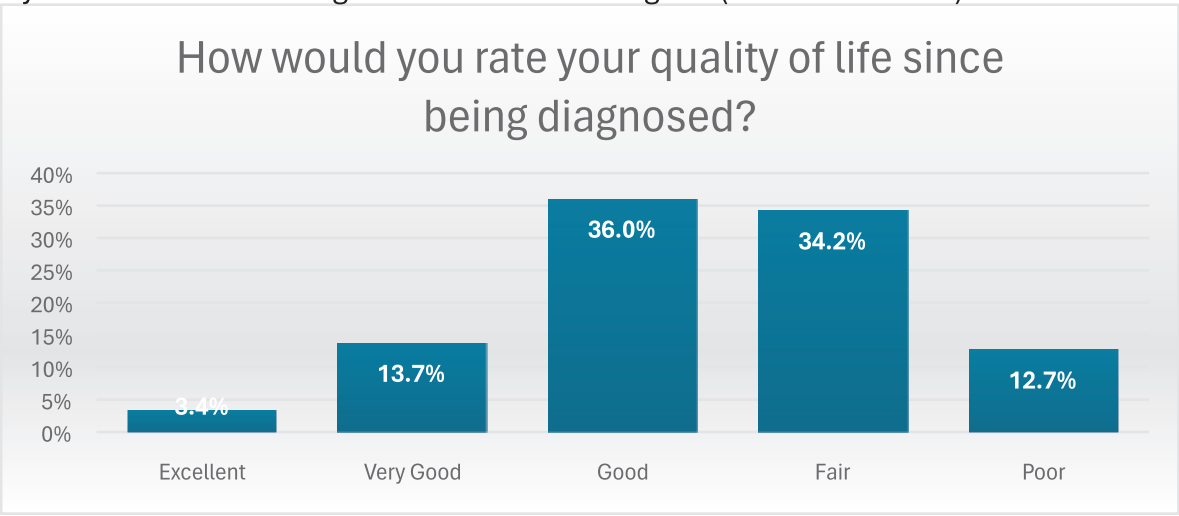
Activities such as educating themselves or others (0.9 hours/week), managing finances related to care (0.9 hours/week), advocating (0.8 hours/week), and communicating with providers, insurers, or support systems (0.7 hours/week), though smaller individually, together represent an additional burden.

This finding underscores that HSP/PLS imposes not only physical challenges, but also a significant "time tax" on daily life, where patients and families must constantly monitor, plan, and advocate just to maintain basic care and quality of life.

Review of Section 5: Quality of Life and Outlook

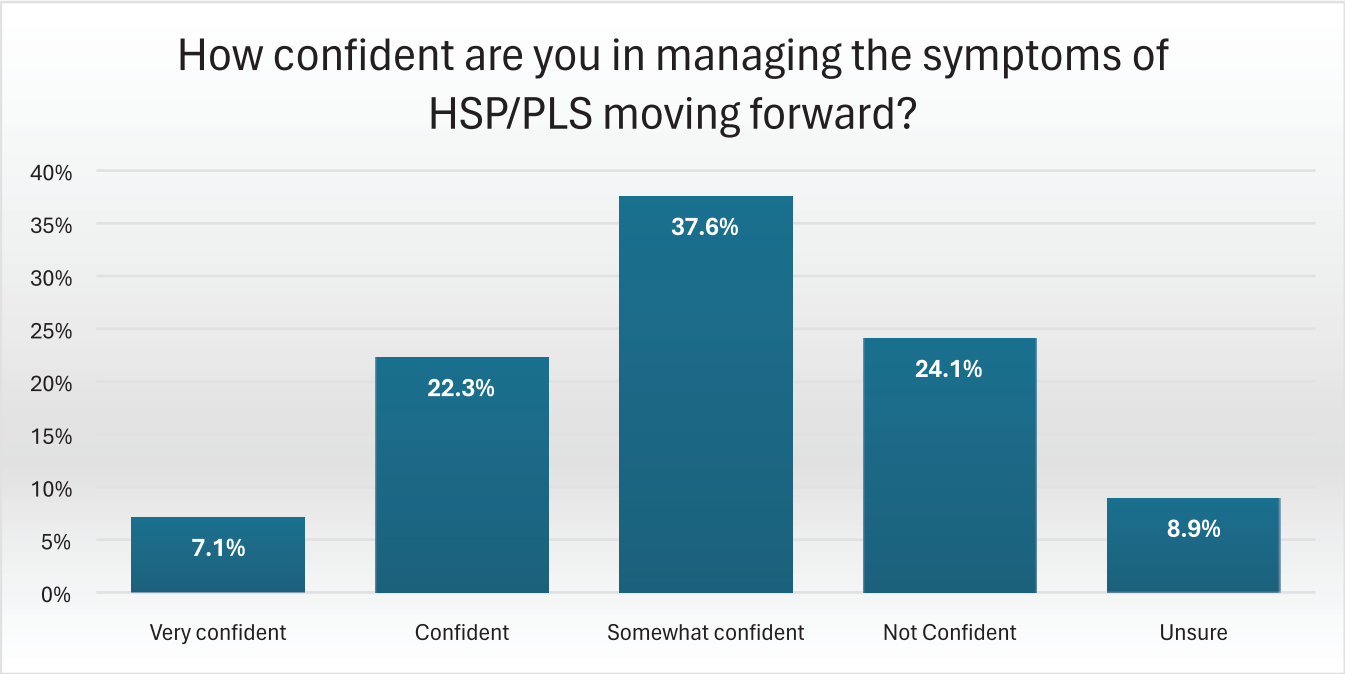
"I am tired of having to educate my doctors about my illness. I am tired of every specialist not understanding that my neuromuscular disease affects everything - my mental health, my gastrointestinal system, my sleep architecture, etc. It is exhausting enough having PLS. It is more exhausting and infuriating that the medical "professionals" in this country are so ignorant and refuse to educate themselves or treat a PLS patient as a whole person and not just a bunch of random specialty problems." - patient

S5-1. How would you rate your quality of life since being diagnosed?
About a third of respondents rate their quality of life as 'good' following diagnosis. More respondents rate their quality of life as worse than 'good' than better than good (46.9% vs. 17.1%).



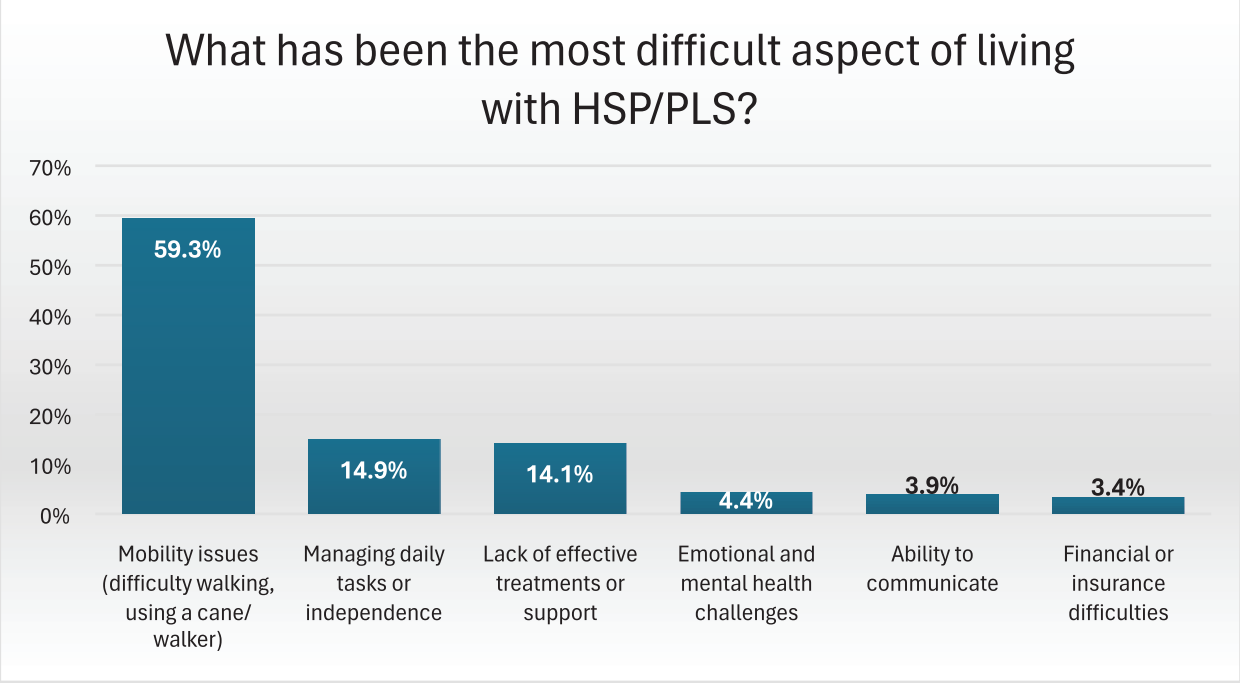
S5-2. How confident are you in managing the symptoms of HSP/PLS moving forward?

Around 4 in 10 respondents feel 'somewhat confident' in managing HSP/PLS moving forward. There is roughly an equal split between those who feel confident or very confident (29.4%) as compared to those who lack confidence or are unsure (33%).

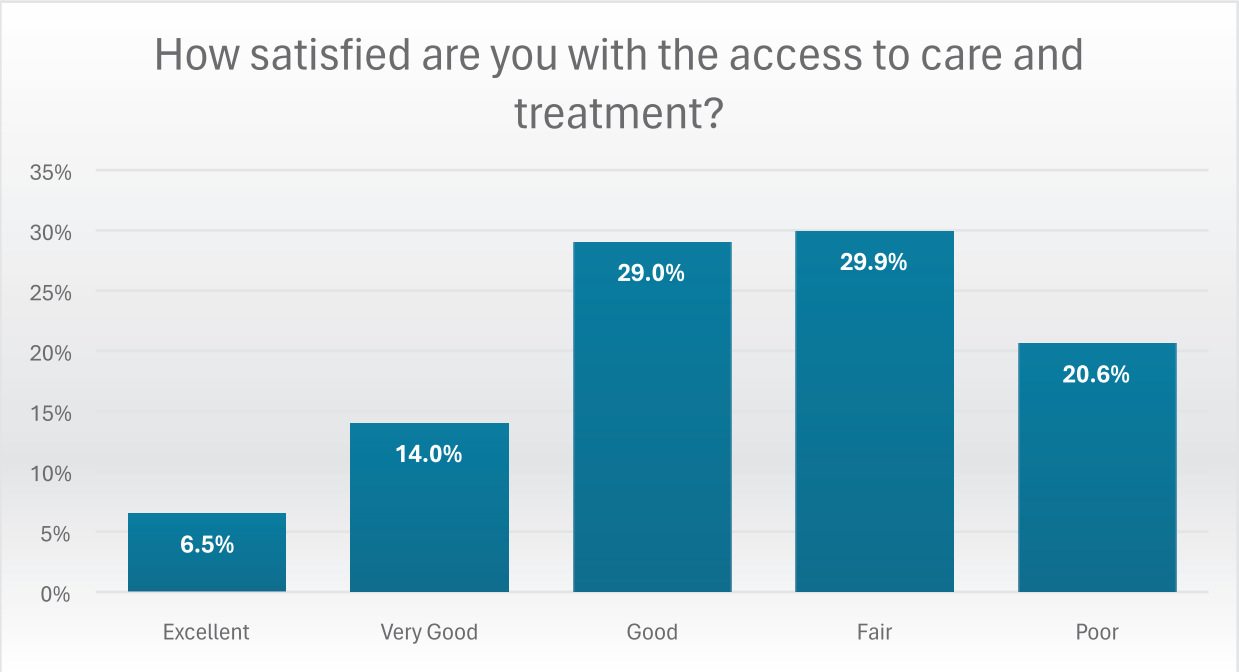


S5-3. What has been the most difficult aspect of living with HSP/PLS?

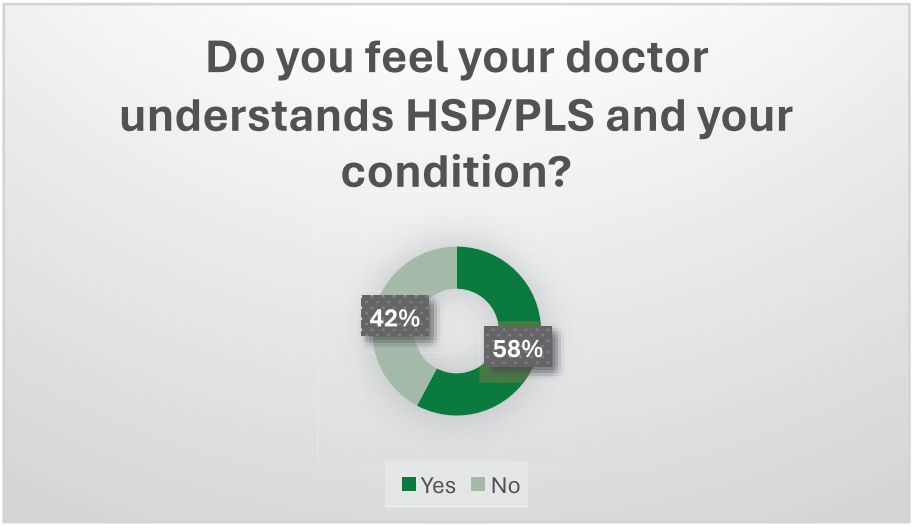
The majority of respondents identify mobility challenges as the most significant difficulty in living with HSP/PLS.



S5-4. How satisfied are you with the access to care and treatment you or those you care for are getting for HSP/PLS?
Respondents express significant dissatisfaction with access to care and treatment. Only 20.5% rate their care and treatment as very good or excellent, while over 50% consider it fair or poor, highlighting substantial gaps in patient access and support.

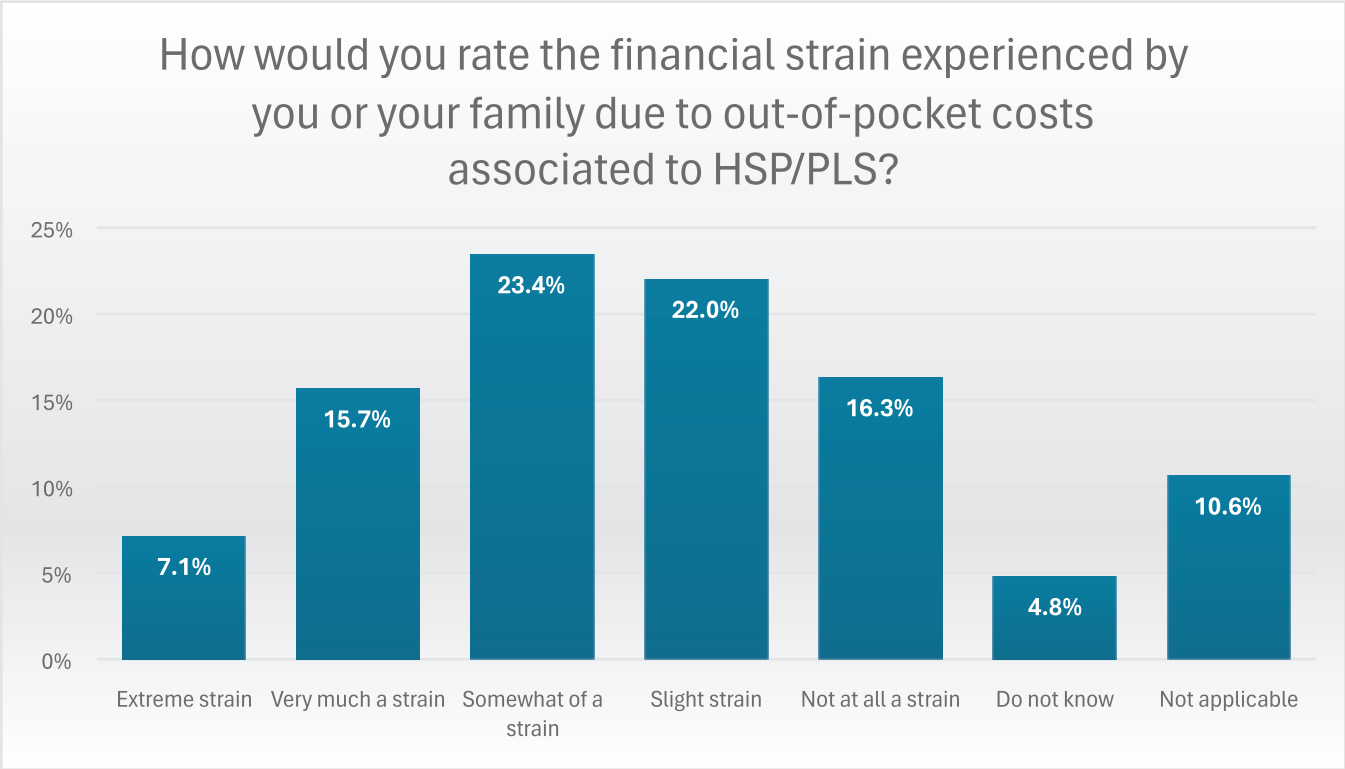


S5-5. Do you feel your doctor or service provider understands HSP/PLS and what you are dealing with in your day to day life?
While nearly 6 in 10 respondents feel their doctor understands HSP/PLS and the challenges of daily living, a substantial 42% report that their physician does not fully grasp the complexities of the condition and its impact on patients' day-to-day lives, underscoring an urgent need for increased provider awareness and education.



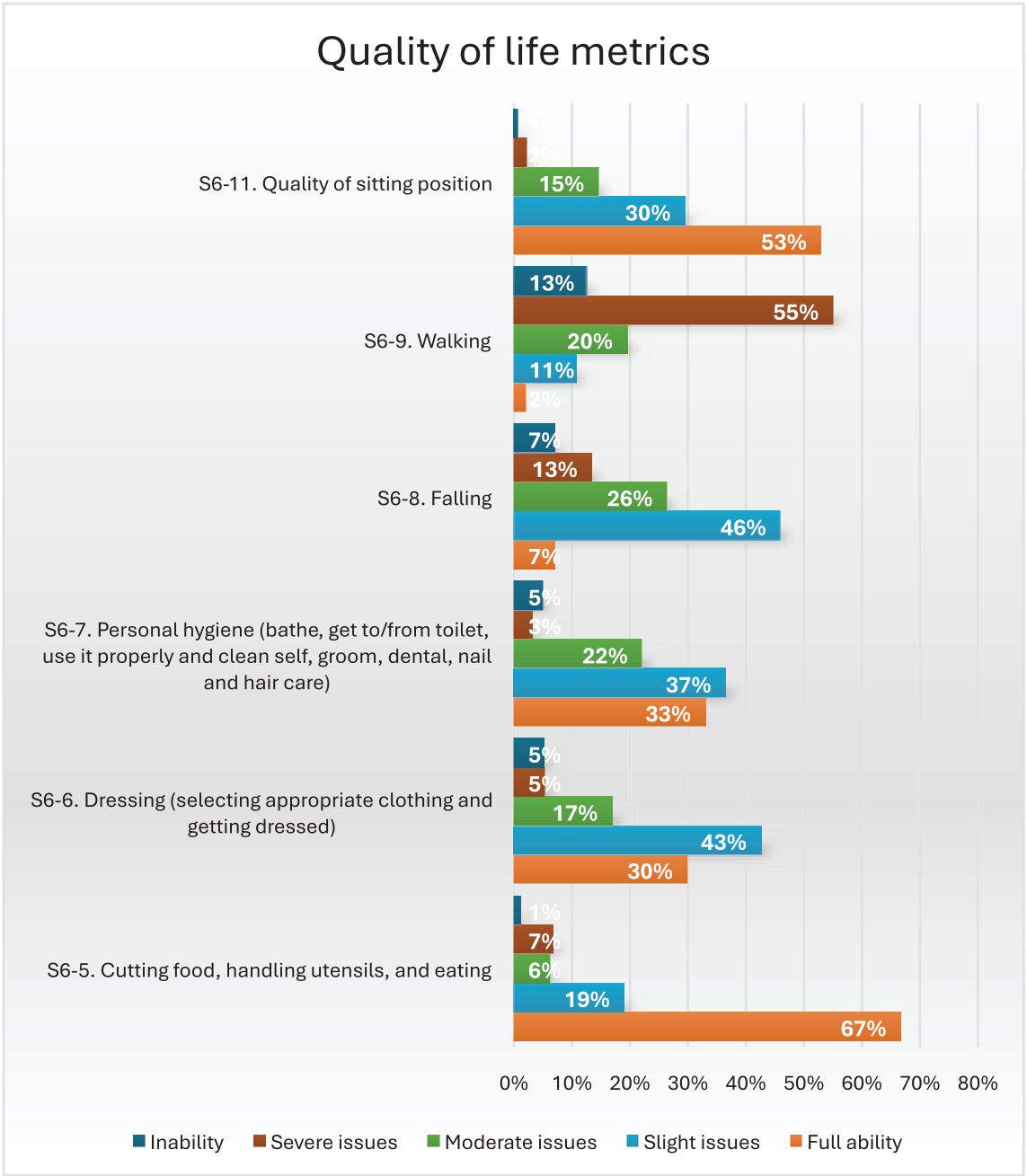
S5-6. How would you rate the financial strain experienced by you or your family due to out-of-pocket health care costs that are related to the HSP/PLS?

The survey reveals that the financial impact of living with HSP and PLS is substantial. Nearly half of respondents—46.2%—report that out-of-pocket healthcare costs create at least somewhat of a strain to extreme financial strain on themselves or their families. These findings highlight that, beyond the physical and emotional challenges of HSP/PLS, patients face a significant economic burden. Understanding and addressing these costs is essential to improving overall quality of life and ensuring equitable access to necessary care and therapies.



Quality of Life Impact:

For individuals living with HSP/PLS, daily life is profoundly shaped by progressive mobility loss and the challenges it creates. Walking difficulties are the most dominant issue, with more than half of respondents (55%) reporting severe impairment and an additional 13% unable to walk at all. The risk of falling is a constant and pervasive concern, as one-third of patients report moderate to severe falls, and nearly half live with the ongoing strain of frequent minor falls. Even tasks of daily living such as dressing independently are compromised, with nearly one in four respondents experiencing moderate to severe difficulty. These metrics paint a sobering picture: HSP/PLS not only robs mobility, but also erodes autonomy and safety, placing relentless strain on quality of life and demanding urgent attention for more effective treatments and supportive care.

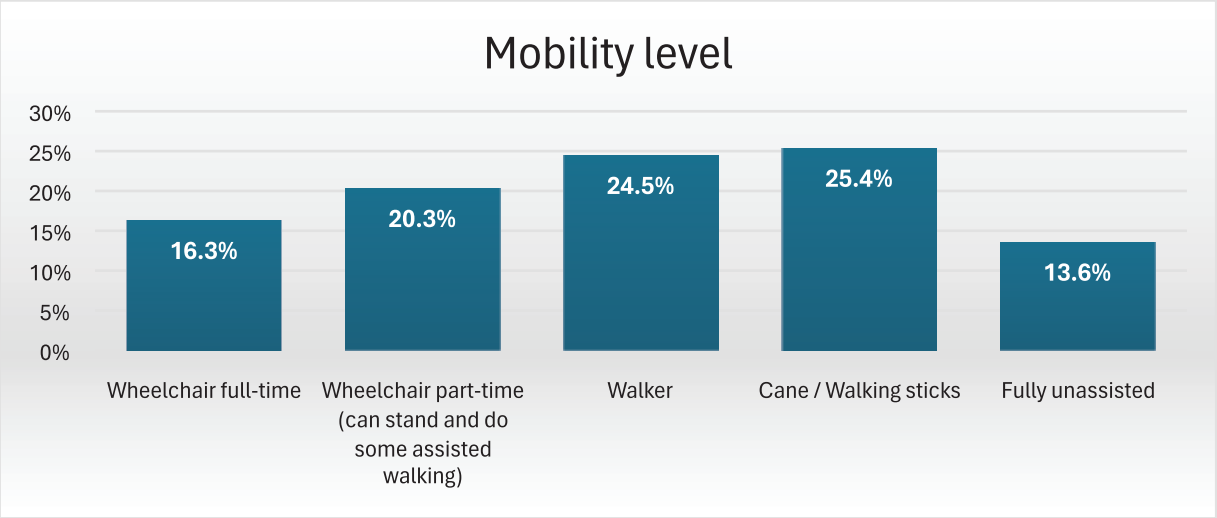


Review of Section 6: Daily Activities

"I feel like I spend the majority of my life managing my disability, disease and being concerned with how it impacts and limits the quality of my life, as well as impacting my mental health and optimism about my future enjoyment of life. My life would be dramatically different without the disease, in every aspect." - patient

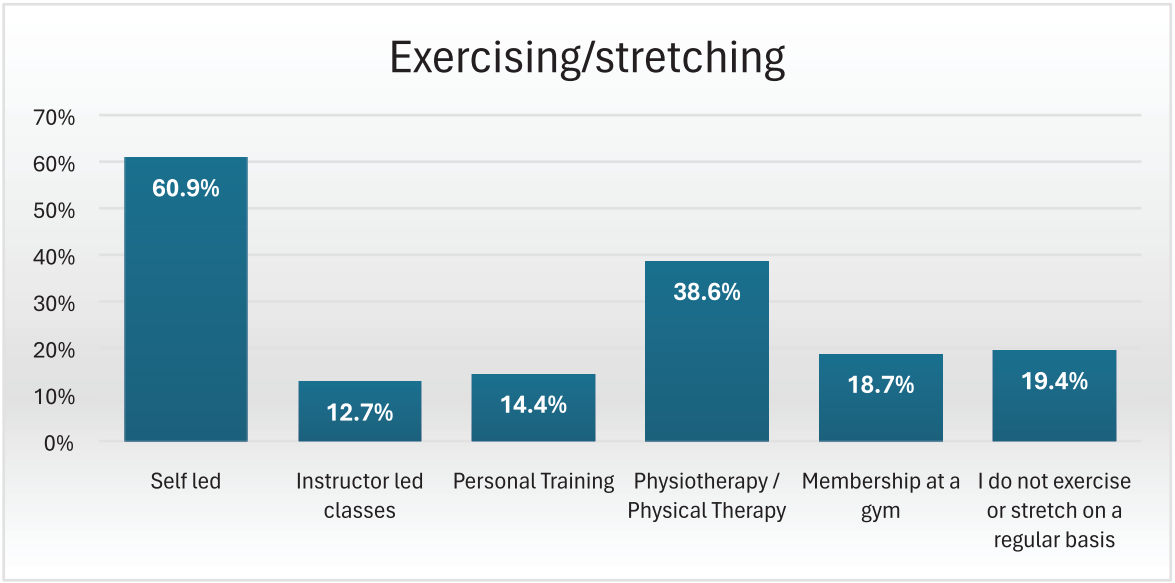
S6-1. Mobility Level

49.9% of all respondents use only a walker or cane as an assistive device. Around 13.6% respondents are fully unassisted, while 36.6% use a wheelchair either part-time or full-time.



S6-2. Exercising / Stretching (Select all that apply)

6 in 10 respondents engage in self-led exercise, while 4 in 10 participate in some form of physical therapy. 1 in 5 does not exercise or stretch on a regular basis.

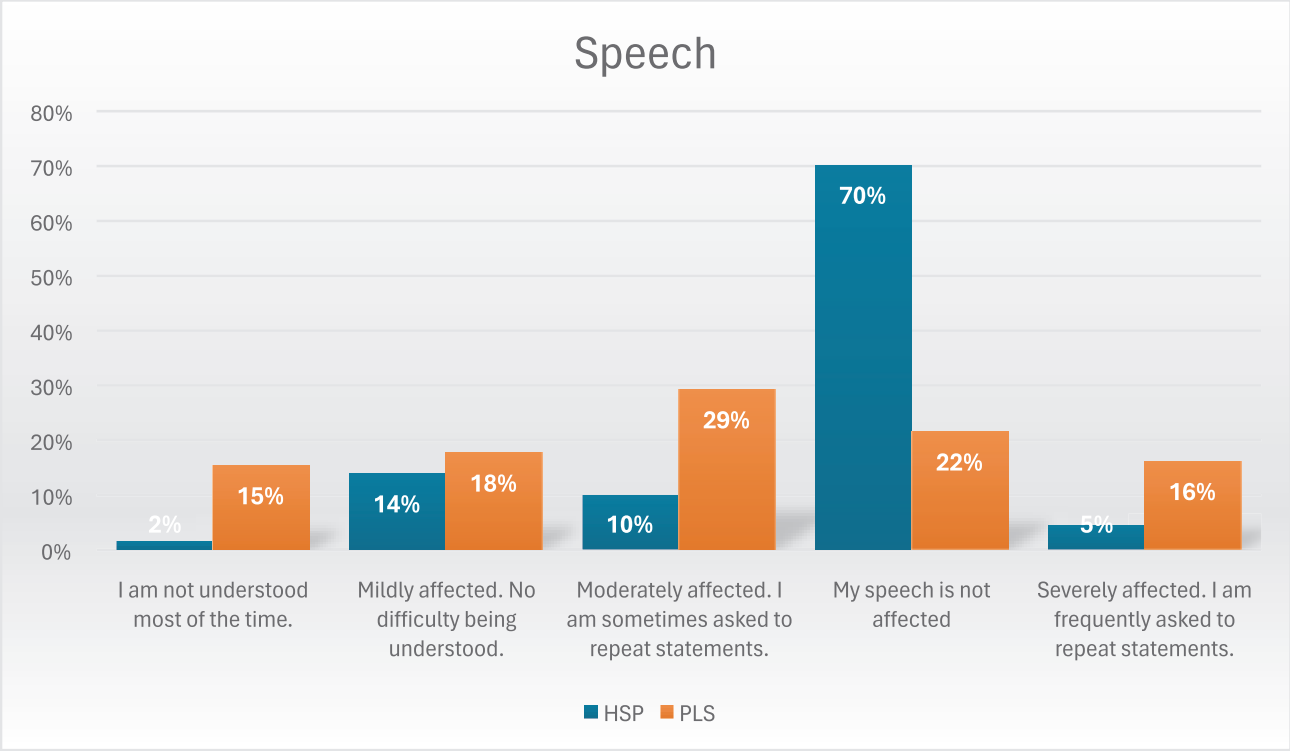


S6-2a. If you exercise, how often?

Around 3 in 10 respondents exercise between 1 and 3 hours per week, making this the modal category response, followed by 1 in 4 respondents who exercise between 4 and 6 hours per week. Those who average at least one hour per day over the course of the week include 1 in every 6 respondents.

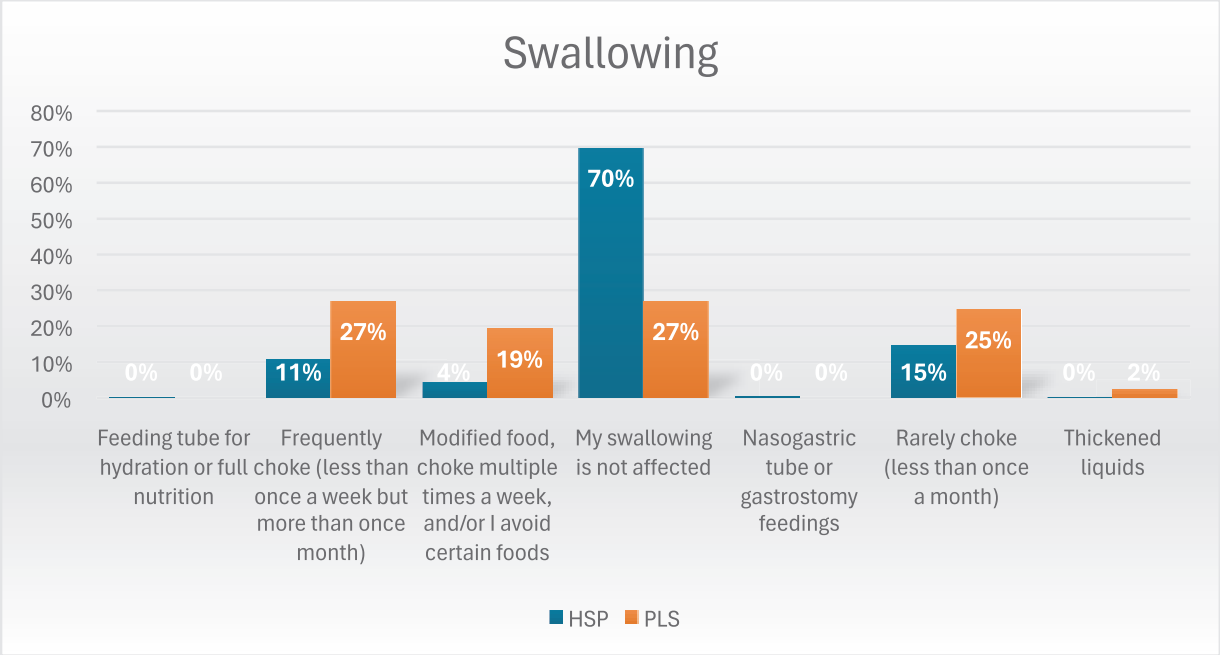
S6-3. Speech

Speech challenges are a profound burden for many living with HSP and PLS. Nearly 4 in 10 respondents report moderate difficulties, and 1 in 5 describe their speech as severely affected, barriers that can make everyday communication exhausting and, at times, isolating. Even for those mildly affected (15.3%), the struggle to be clearly understood (4%) underscores the constant emotional weight of not having one's voice fully heard.



S6-4. Swallowing

Swallowing difficulties are a daily struggle for many in the HSP/PLS community. 6.7% of all survey respondents responded that they require modified food. These numbers reflect more than statistics—they represent the constant fear, frustration, and risk that turn a simple meal into a challenge, affecting both safety and quality of life.

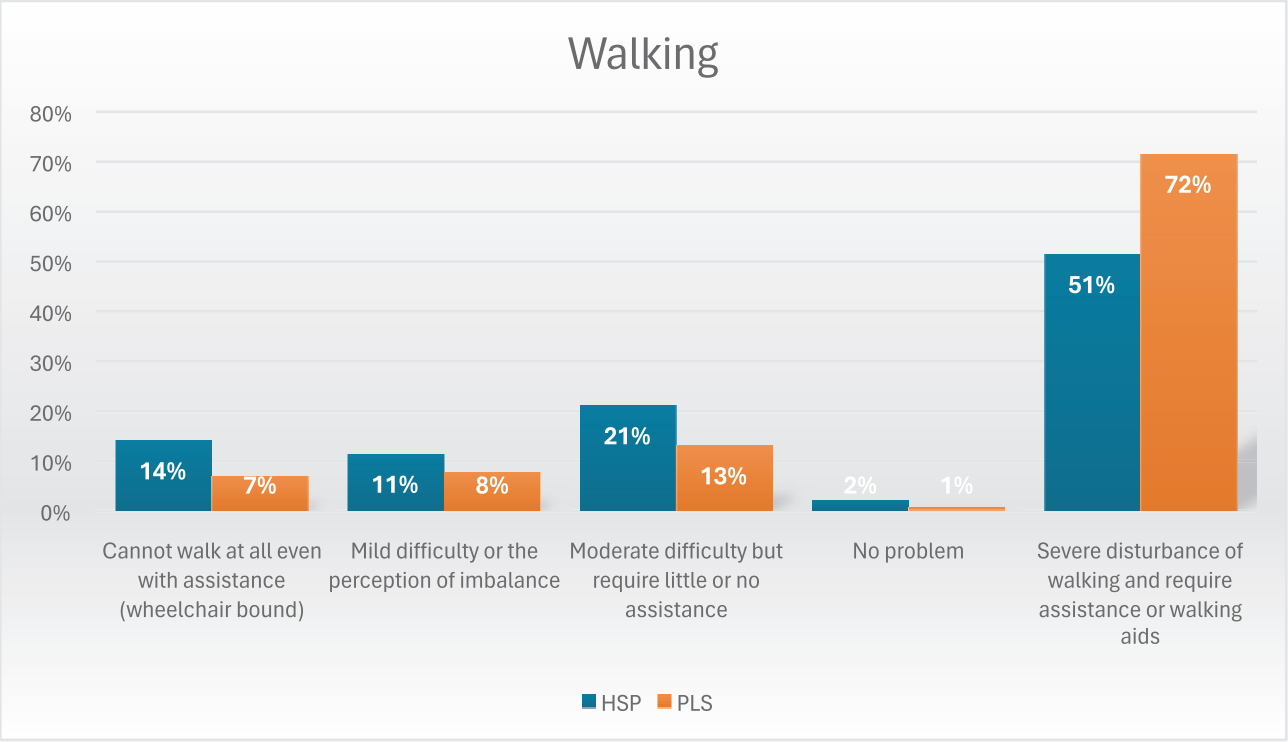


S6-9. Walking – Moderate difficulty but require little or no assistance

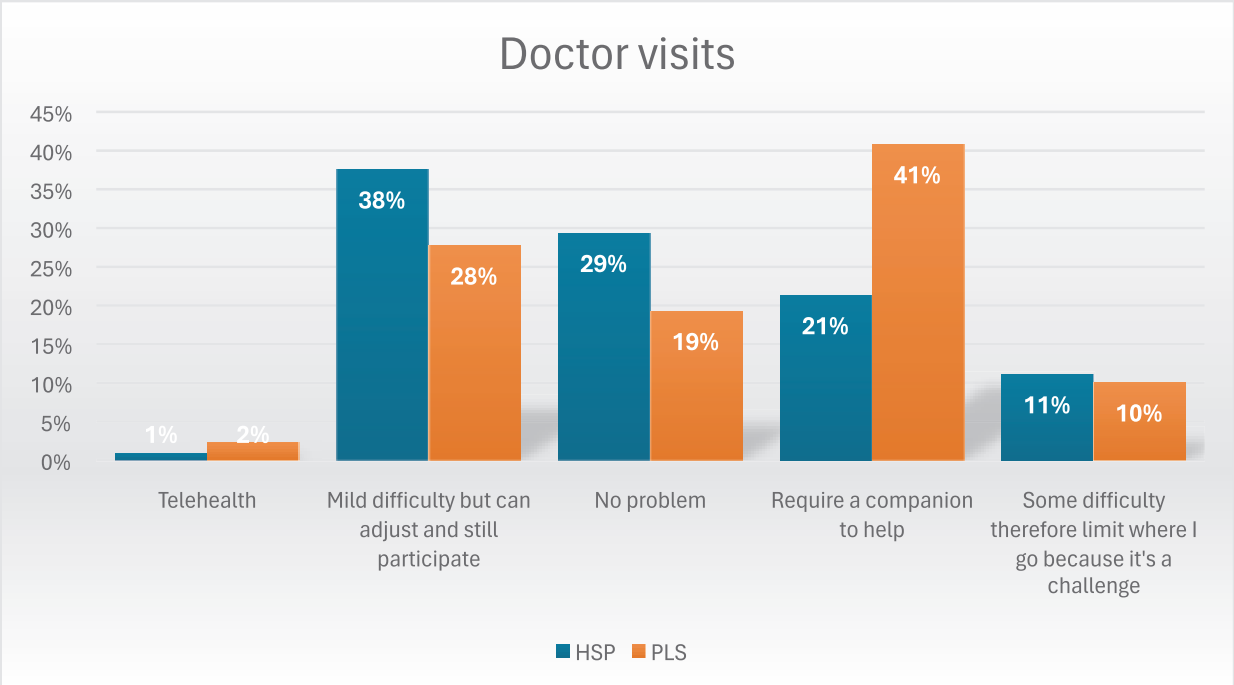
Walking is one of the most profoundly impacted abilities for people living with HSP and PLS. For those who can walk unassisted, nearly 3 in 4 respondents find it difficult to focus on anything else while attempting to walk.

S6-10. For those that can walk unassisted, is it difficult to walk and talk or focus on things other than walking without stumbling or falling?

More than half of respondents (55%) report severe walking disturbances requiring assistance or mobility aids, and 13% are unable to walk at all, relying on wheelchairs. While some experience only mild difficulty and others (20%) moderate challenges, these numbers underscore the reality that for the majority, mobility loss is not a distant possibility—it is a daily reality that shapes independence, dignity, and quality of life.

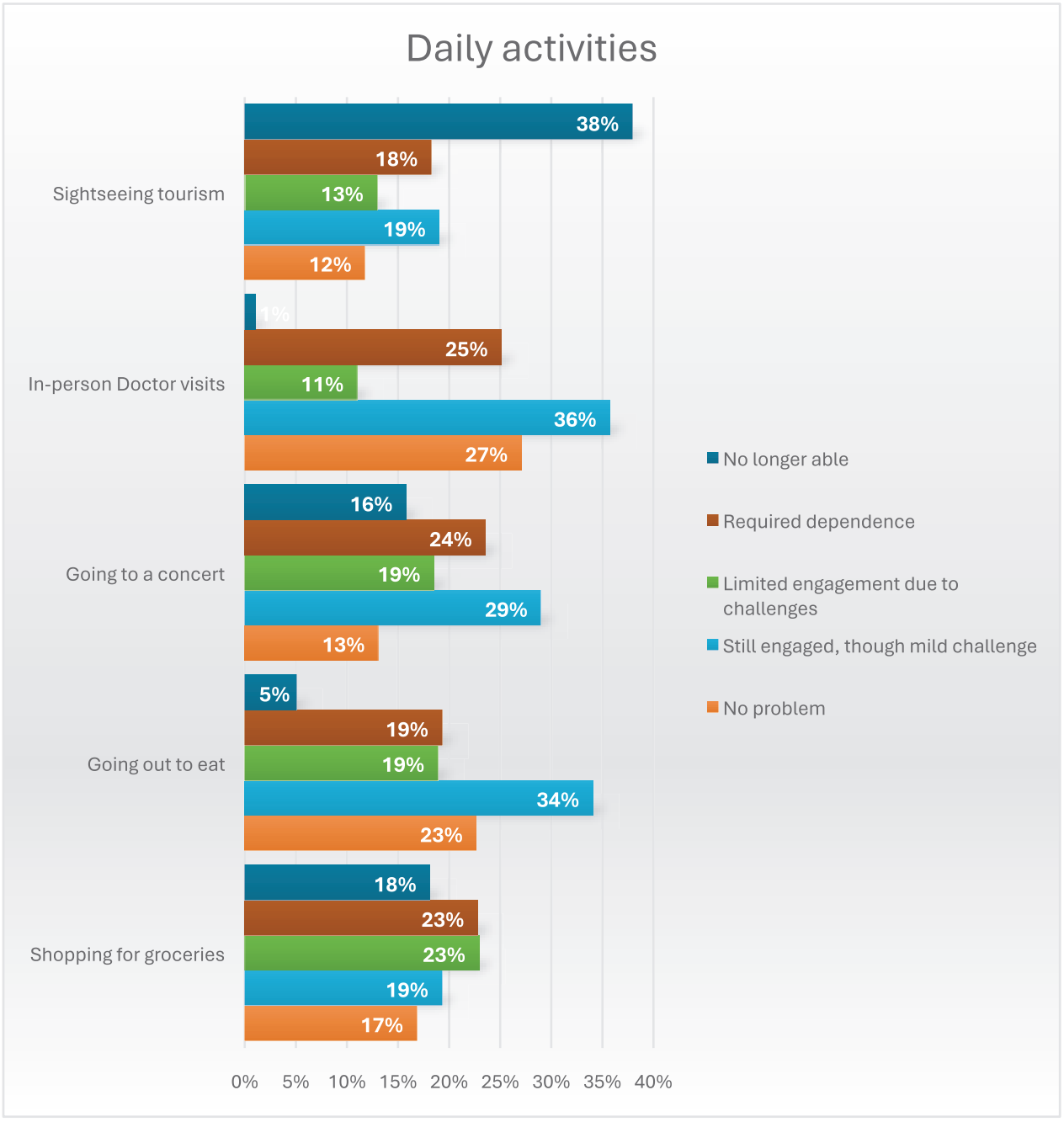


S6-16. Doctor visits



Daily Activities: A Steady Loss of Independence

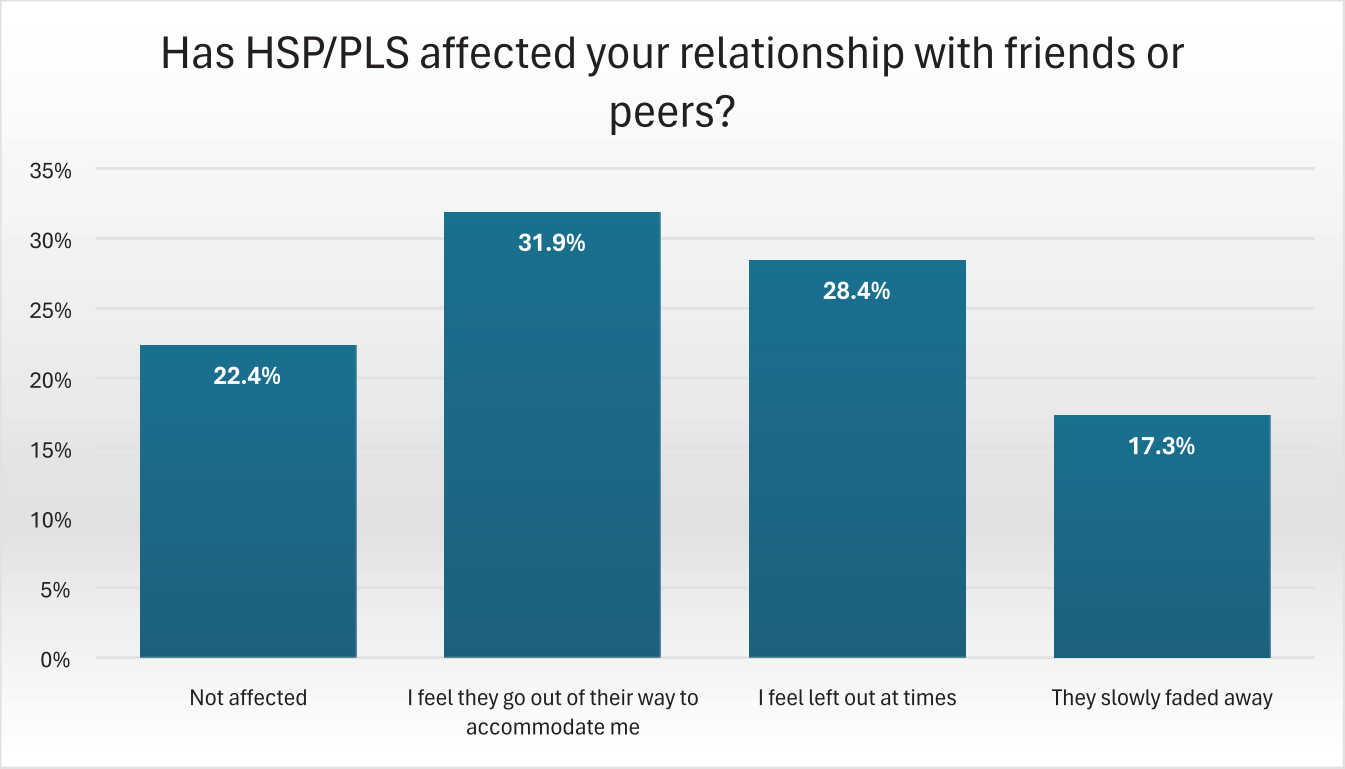
Survey responses reveal just how deeply HSP/PLS reshapes the ordinary rhythms of life. Activities that many take for granted—such as sightseeing, attending concerts, or even grocery shopping—become increasingly out of reach. **Tourism and leisure activities are particularly impacted**, with more than half of respondents either unable to participate (38%) or reliant on others (18%). Even essential tasks like **grocery shopping** show heavy dependence, with nearly two-thirds unable, reliant, or severely limited. Social connection is also diminished: **attending concerts** and **going out to eat** both show high levels of dependence or limited engagement, underscoring how mobility loss and accessibility barriers isolate patients from cultural and family life. Even **doctor visits**, an essential part of disease management, require dependence for one in four respondents. Together, these findings highlight the relentless erosion of independence and the emotional toll of losing everyday joys, reinforcing the urgency of therapies and supportive interventions that restore not just mobility, but dignity and quality of life.



Review of Section 7: Relationships and Work

"My life is very lonely and without my mother's help and support I don't know what I would do. People don't understand how this has affected my schooling, my education, work opportunities and has greatly affected my ability to earn money. Dreams are lost in the process of not being able to support myself without help from others." - patient

S7-1. How has living with HSP/PLS affected your relationship with friends or peers?
Living with HSP/PLS takes a significant emotional toll: while only about one quarter of respondents feel their friendships remain unaffected, nearly half (45.8%) experience feelings of isolation or notice relationships gradually fading, reflecting the profound social impact of these conditions.

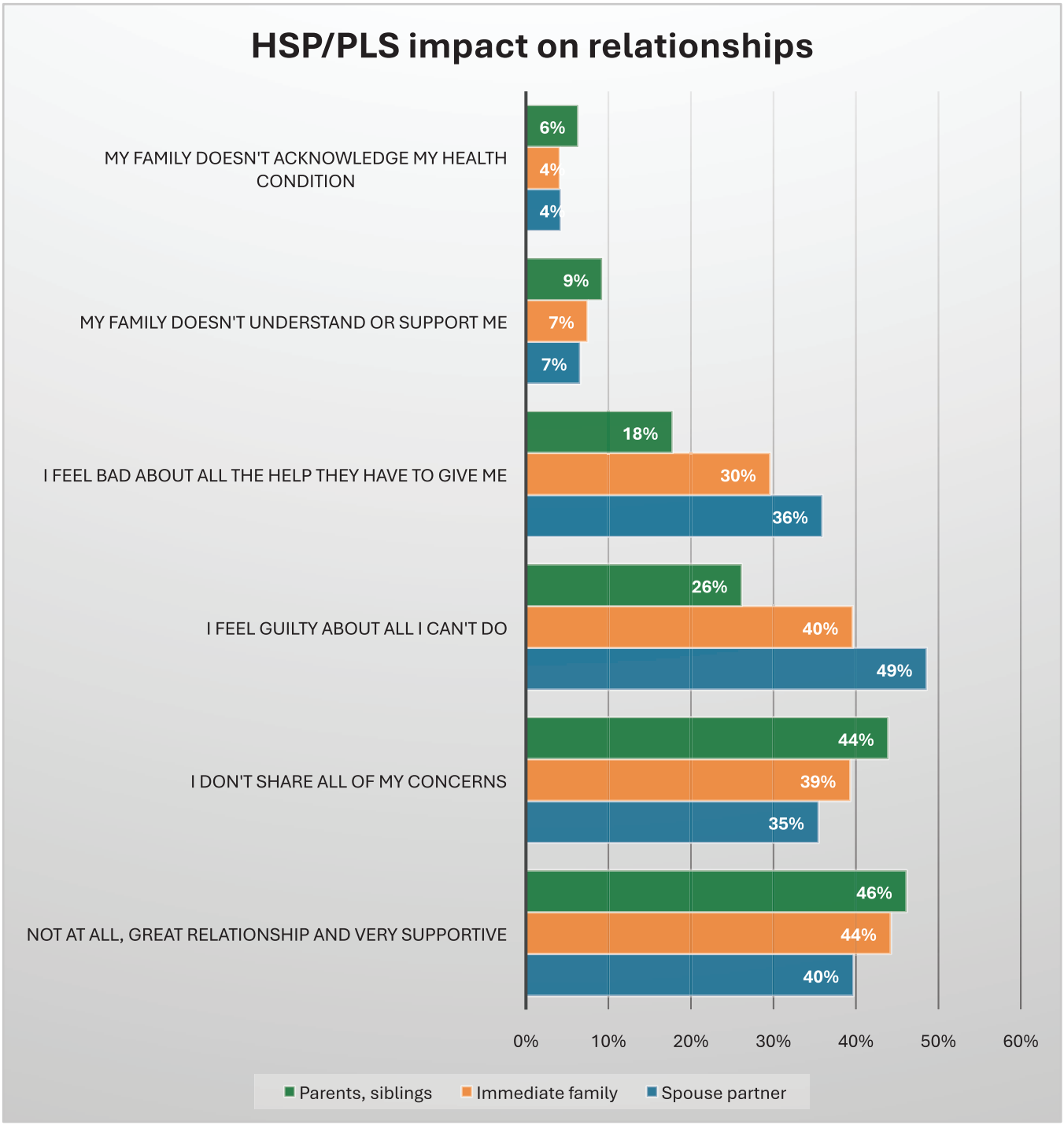


S7-2. Do you feel HSP/PLS influences or changes other people's perceptions of you?
The vast majority of respondents (83%) feel that HSP/PLS changes how others see them—highlighting not only the visible challenges of the disease but also the invisible weight of stigma, altered relationships, and loss of identity that patients carry.

S7-4. Do you feel bad because others go out of their way to help you?
More than half of respondents (54%) reported feeling guilty or burdened because they must rely on others for help—underscoring the emotional strain of needing assistance for daily life.

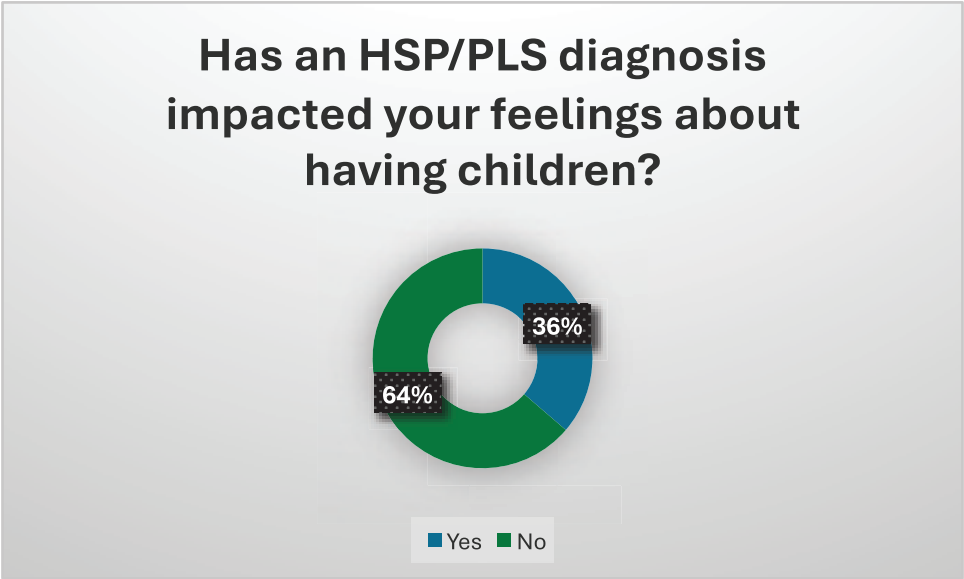
S7-5, 6, 7

Responses convey differing aspects of relationships and don't necessarily operate on a continuum. Generally, the categories sorted into aspects of positive support, withholding concerns, guilt about limitations, burden of caregiving, lack of understanding or support, and not acknowledging condition. Spouse/partners are both the greatest source of guilt and burden, but not necessarily less supportive. Parents/siblings are perceived as most supportive overall, but also where respondents are least likely to share concerns. Immediate family sits in between, often closer to spouse/partners in responses.



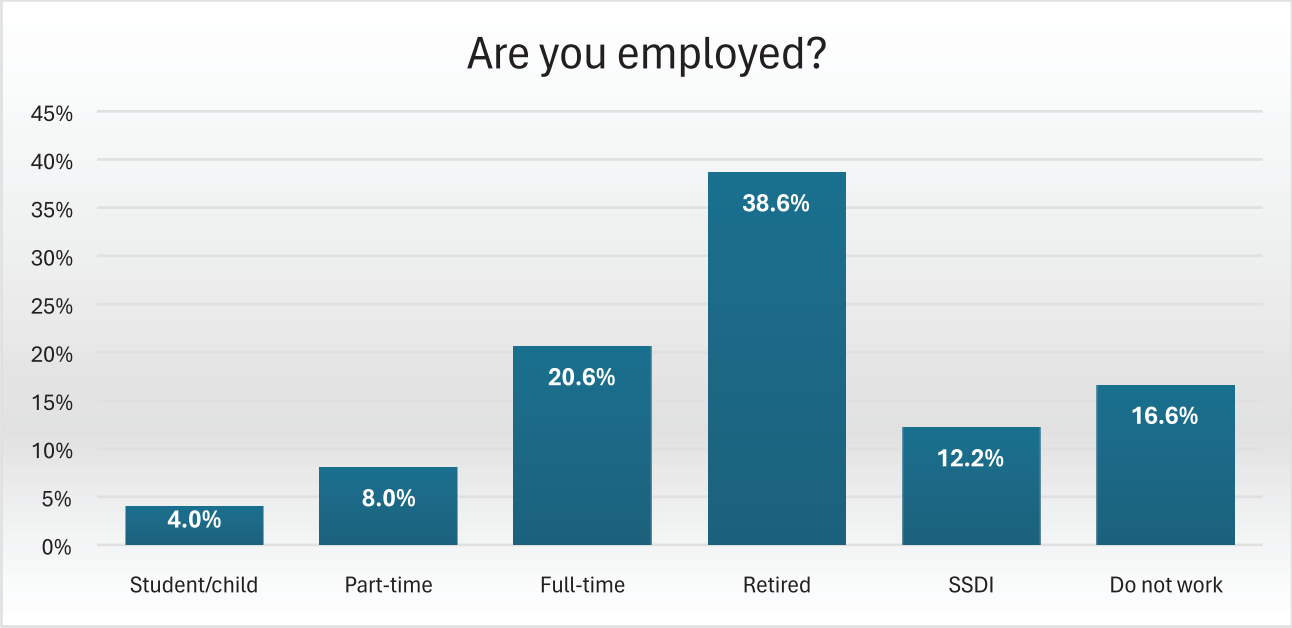
S7-8. Has an HSP/PLS diagnosis impacted your feelings about having children

Nearly 2 in 3 respondents feel their diagnosis has not impacted their feelings about having children. This number might be biased based on the age of respondents submitting a response to this question.



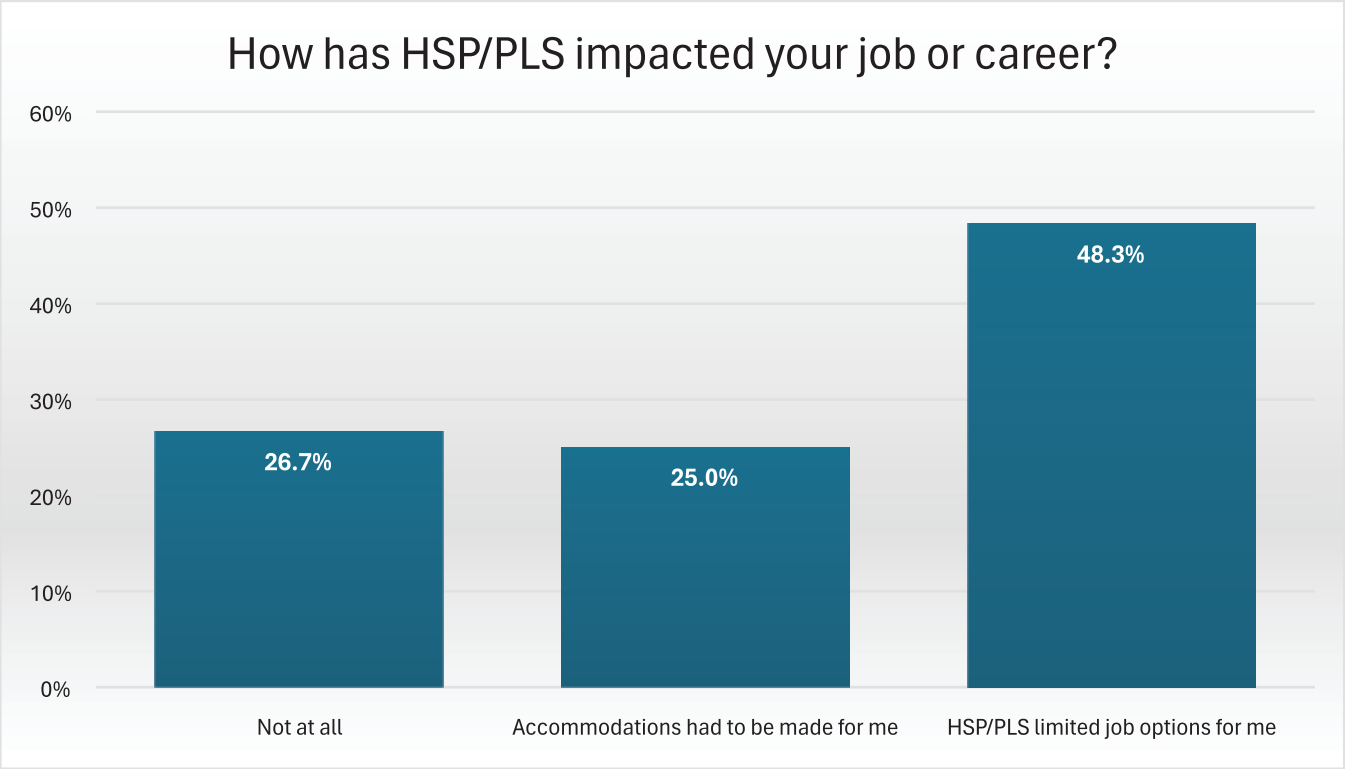
S7-9. Are you employed?

Nearly 4 in 10 survey respondents are retired, while 1 in 5 is working full-time.



S7-10. Considering your current or previous job (if not currently working), to what extent do you feel HSP/PLS has impacted your job or career?

Most respondents (48.3%) feel their diagnosis has limited their job options.



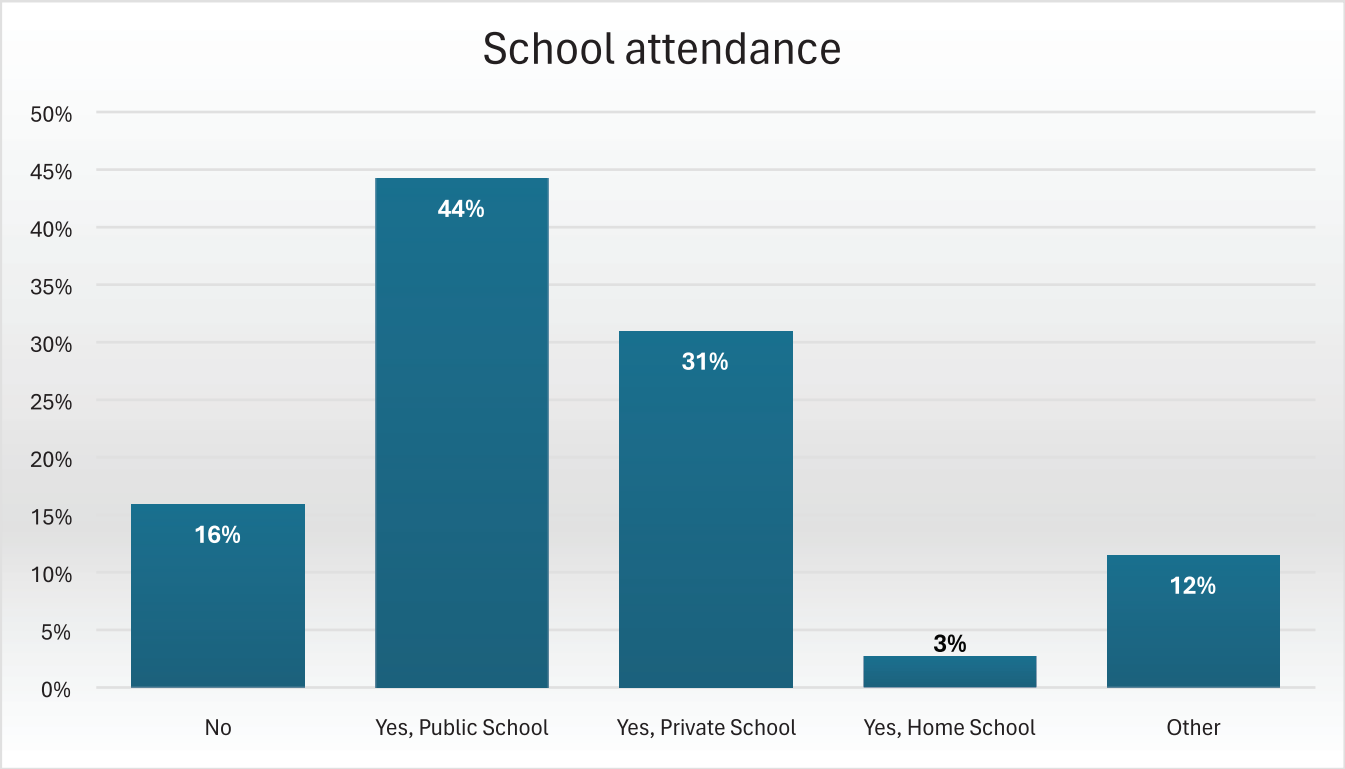
S7-11. Do you feel HSP/PLS affected your work productivity (e.g., getting work accomplished, focusing as you would like or being present for your desired schedule)?

61% of respondents feel their diagnosis affected their work productivity.

Review of Section 8: Specific to Childhood Onset

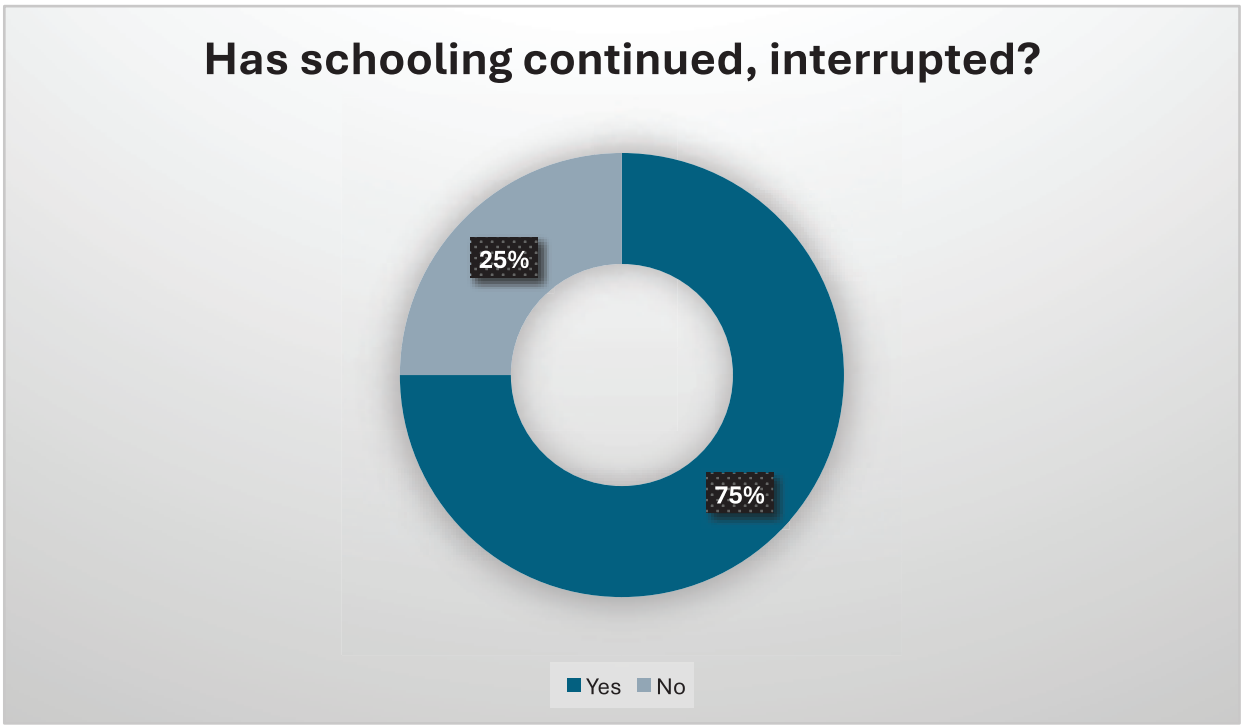
Questions in this section were meant specifically for parents with children currently dealing with HSP. We saw significant responses that appeared to be completed by patients that had symptoms starting in adulthood and may have not realized this section should have been skipped. Therefore, we are not confident in the value of the survey results received. This underscores the need for continued research and increased participation from the childhood onset community to better understand their lived experience. 86 responses and only 49 parents responded.

S8-1. Has your child attended school, what type?



S8-3. Has schooling continued, uninterrupted?

For children with early-onset HSP, the toll is profound—three out of four respondents reported that schooling was disrupted, altering the course of education and daily life.



S8-3a. If you answered YES, please explain.

Among the 51 respondents describing the impact of childhood-onset HSP on education, experiences varied widely, but clustered into five key themes. Half of respondents (25) reported that schooling continued without major issues, suggesting that some children can navigate their education with minimal disruption. However, for the other half, HSP clearly reshaped the educational journey. Ten children required special education or classroom accommodations, while another 10 shifted to homeschooling or alternative educational paths to meet their needs. In an equal number of cases (10), HSP itself—whether confirmed or strongly suspected—was specifically cited as a direct influence on school performance. Notably, six families reported school disruption due to medical or emotional issues tied to HSP, underscoring the complex ways the disease affects not only mobility but also mental health, confidence, and continuity of learning.

These findings highlight that even when education is technically "completed," many children with HSP face an altered or interrupted path that affects both social and academic development.

Category	Frequency Count
Schooling Without Issues or Interruptions	25
Special Education / Accommodations	10
Homeschooling & Alternative Education	10
HSP Mentioned (Direct or Suspected)	10
School Disruption Due to Medical or Emotional Issues	6

S8-4. Does your child have any intellectual disabilities, please describe?

Seventy-nine families responded to the question of whether their child with HSP/PLS has any intellectual disability. The most common response—nearly two-thirds of answers (46)—was that no intellectual disability was reported. This is an important finding, as it underscores that many children with HSP experience challenges primarily in mobility and physical function, without cognitive impairment.

At the same time, the remaining responses paint a very different picture for a significant subset of families. Confirmed intellectual disabilities were described in various forms, ranging from low IQ, mild intellectual disability, and global developmental delay to more severe impairments including nonverbal status. Learning and processing disorders, such as dyslexia, slow processing, and receptive/expressive language delays, were also noted, as were issues with emotional regulation (including ADHD/ODD). Some families reported suspected or undiagnosed conditions—including autism spectrum disorder, memory loss, or possible gene-related cognitive impairment—highlighting ongoing uncertainty and the need for further evaluation.

Taken together, these responses reveal that while intellectual disability is not universal in HSP/PLS, when it does occur, it has a profound impact on education, daily life, and family well-being. These findings emphasize the need for better research into the neurological spectrum of HSP/PLS, as well as expanded access to neuropsychological assessment, individualized educational supports, and early intervention for children at risk.

ACKNOWLEDGEMENTS:

The 2025 SPF HSP/PLS Patient History Survey was created by patients, for patients, at the request of the Spastic Paraplegia Foundation (SPF). This effort represents countless hours of volunteer work, lived experience, and collaboration to ensure the voices of individuals and families living with Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS) are heard and recognized in research and therapeutic development.

Survey Team

The Spastic Paraplegia Foundation extends its deepest gratitude to each of these individuals and to the broader HSP/PLS community, whose input and support made this survey possible.

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Dina Landphair, SPF Board Member (SPG7)
Sue Duffy, SPF Ambassador for Florida (SPG4)

Tracy Hood, SPF Ambassador for Florida (SPG5A)
Christine Hendrickson, SPF Ambassador for Florida (SPG7)
Hank Chiuppi, SPF Board Member (PLS)

Dr. Michael Kaplan, SPF Ambassador for Florida (Parent of child with SPG49)
Dr. David Perkins, President, Beyond Green Sustainability LLC. Results analysis

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●National Institutes of Health. *All of Us Adds Data from 50% More Participants in Largest Data Expansion to Date. Precision medicine effort strengthens its platform for groundbreaking discoveries.* Bethesda, MD: 2025 NIH. Available at: https://allofus.nih.gov/article/announcement-all-of-us-adds-data-from-50-more-participants-in-largest-data-expansion-to-date

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Executive Summary

The 2025 Spastic Paraplegia Foundation (SPF) HSP/PLS Patient History Survey captures the lived experiences of individuals and families affected by Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). With 770 respondents worldwide, this survey provides an unprecedented, patient-driven dataset detailing the clinical, functional, emotional, and social impacts of these rare disorders.

Loss of Mobility: A Resounding Cry for Help

The Survey captures the voices of individuals and families living with Hereditary Spastic Paraplegia (HSP) and Primary Lateral Sclerosis (PLS). Their responses tell a clear and devastating story: lives defined by progressive loss of mobility, dependence on assistive devices, and a relentless search for treatments that do not yet exist.

More than **94% of respondents report difficulty walking**, compounded by staggering rates of stiffness, spasticity, weakness, and balance loss. Over time, these symptoms erode independence and confine lives to canes, walkers, wheelchairs, and scooters. Families describe this progression as one of the most painful and visible losses—mobility stripped away step by step, leaving patients desperate for relief.

Lives Defined by Wheels and Supports

The data show a heavy reliance on assistive devices: **45% use walkers, 40% wheelchairs, and 31% canes**, with many reporting multiple devices used as disease advances. For children, this reality disrupts education, friendships, and life milestones. For adults, it reshapes careers, family roles, and daily living. The patient and family voice resounds with one message—without effective treatments, devices are lifelines, but they are also symbols of lost independence.

Exhausting Every Option, Yet Still Without Relief

Nearly all respondents (**97%**) have consulted neurologists, and the vast majority have seen physical therapists, occupational therapists, urologists, and psychologists. Families identified **349 specialists**, yet the best interventions reported are physical therapy, symptom-managing medications, and occasional use of procedures such as Botox. While these provide some temporary relief, they do not halt progression. Families report a relentless cycle of appointments and therapies yet continue to face worsening disability and dependence.

A Relentless Search for Care Without Lasting Solutions

This survey reveals both the courage and the desperation of the HSP/PLS community. Families are not disengaged—they are fatigued with the lived experiences of disease progression, exhausting the healthcare system in search of answers, and increasingly frustrated with the healthcare industry's inability to provide meaningful solutions. The burden is not just physical, but emotional, financial, and social. Patients want to live, work, and contribute fully, but the lack of disease-modifying treatments makes this impossible.

The Call to Action

The survey results elevate a single truth: HSP and PLS are devastating diseases that demand urgent clinical and research attention. The patient community is already deeply engaged in care, but symptom management alone is not enough. Clinicians, researchers, and industry leaders must join forces to accelerate discovery—repurposing existing drugs, testing novel therapies and biologics, and developing better interventions that not only address the root of these conditions but also deliver impactful treatments for the devastating symptoms revealed in the survey. The message is clear: **Families living with HSP/PLS cannot wait. Every year without progress means more lost mobility, more reliance on wheelchairs and aids, and more futures disrupted.** This survey is not only data—it is a collective cry for help, a mandate for action, and an urgent call to bring hope where today there is only coping.

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