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Progressive Supranuclear Palsy **Voice of the Patient Report**

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Report submitted to the U.S. Food and Drug Administration (FDA)

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Voice of the Patient Report on Progressive Supranuclear Palsy

This *Voice of the Patient* report has been published by CurePSP as a summary of the input shared by individuals living with progressive supranuclear palsy (PSP) and their loved ones during an Externally-Led Patient Focused Drug Development (EL-PFDD) meeting on PSP. The meeting was conducted virtually on February 6, 2026. CurePSP is a nonprofit public charity focused on research, support, education, and advocacy for people impacted by PSP, corticobasal degeneration (CBD), and multiple system atrophy (MSA). The mission of CurePSP is to raise awareness, build community, improve care, and find a cure for PSP, CBD, and MSA by providing direct support to patients and care partners by educating family, the public, and healthcare professionals.

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Executive Summary: **PSP Insights**

Progressive supranuclear palsy (PSP) is a rare progressive neurodegenerative disease characterized by dysfunction in the brain regions controlling movement, balance, swallowing, speech, eye movements, and cognition. Symptoms begin after age 40, with average onset in the mid 60s. From when symptoms first start to death, is estimated to be six to seven and a half years.

Those living with PSP experience many different symptoms, with balance and mobility issues including falls, choking or difficulty swallowing, and speech difficulties as the most troublesome. Poll respondents each experience an average of 8.5 different health concerns. Most experience many PSP symptoms at once and the interplay between individual symptoms makes everything more difficult.

PSP is progressive and unpredictable. Many compared PSP to a tsunami or tidal wave, falling off a cliff, a boulder rolling down the mountain or as a process of literally dying in slow motion. Families must adjust to a new normal, with no way to predict when the next decline will come. Some become prisoners of their own bodies, very aware of their PSP-related progression.

Navigating the world becomes more challenging as PSP-related losses impact all activities of daily life, leading to profound social isolation, not only for the person who has the disease but for their care partner as well. Care partners shoulder an enormous PSP care burden. PSP causes devastating changes to primary relationships, amplifying the social isolation.

Those living with PSP experience many fears about further unpredictable symptoms and additional losses. They expressed fears of what an unknown future living with a progressive neurodegenerative disease may bring. Care partners acknowledged how much fear they observed in their loved ones.

People with PSP often receive an initial misdiagnosis. Other diseases of aging make PSP diagnosis and management even more difficult.

Current PSP treatment approaches are limited to symptom management. No approved disease-modifying therapies are available for those living with PSP. Instead, Parkinson's medications, ophthalmic treatments and sleep mediations are used to manage symptoms. Key drawbacks of current treatment approaches are that none stop or slow PSP progression and only work very little or somewhat for most.

As PSP progresses, more and more strategies and approaches to manage symptoms are required. Physical therapy, exercise, structured physical activity, and speech therapy are important for helping to maintain abilities and also provide social support.

Short of a complete cure, the PSP community wants a medication to slow or stop disease progression. They also would like to improve or maintain the ability to swallow, communicate, move, balance, see, and remain independent as long as possible.

The PSP community would like more clinical trials and identified factors that would be important in deciding whether to participate in a new trial. PSP clinical trials must be more inclusive, and clinical trial sites must be localized for easy travel. The PSP community noted that anticipated benefits to participants would need to outweigh potential safety risks in order for them to enroll in a trial.

Introduction

Brief Clinical Summary of Progressive Supranuclear Palsy (PSP)

Progressive supranuclear palsy (PSP) is a rare, progressive neurodegenerative disease, estimated to affect about six individuals per hundred thousand people in the United States.

PSP is caused by deposits of the tau protein in cells in the brain regions that control movement, balance, eye movements, and cognition; however is distinct from other tauopathies such as Alzheimer's disease, frontotemporal dementia, and corticobasal degeneration. PSP is frequently misdiagnosed, most commonly as Parkinson's disease.

Symptoms typically begin after age 40, with average age of onset in the mid 60s. Symptoms worsen gradually over months and years. Key clinical diagnostic criteria include ocular motor dysfunction or trouble with eye movements, postural instability or balance challenges, akinesia or slowness of movement, and cognitive dysfunction or trouble with thinking and memory.

The most common PSP phenotype is PSP-Richardson syndrome which affects about 75% of those with PSP. This type is characterized by ocular motor problems, gait disorder and balance. Other less common PSP phenotypes exist, but they progress differently and can complicate diagnosis.

On average, it takes about four years from the onset of PSP symptoms until someone with PSP is dependent on another for care. From when symptoms first start to death, is estimated to be six to seven and a half years.

PSP EL-PFDD Meeting Summary

The EL-PFDD meeting on PSP was held virtually on February 6, 2026. Patient-focused drug development (PFDD) is a systematic approach to help ensure that patients' experience, perspectives, needs and priorities are captured and meaningfully incorporated into drug development and evaluation. This meeting was an important opportunity for the entire PSP community to share patient and caregiver perspectives regarding the symptoms and daily impacts of PSP, and to discuss current and future approaches to therapies.

The meeting was focused on two key topics: *PSP Symptoms and Daily Impacts* and *Current and Future Approaches to PSP Treatment*. The meeting featured recorded presentations, moderated discussion between individuals on live Zoom panels and those who dialed in by phone. Those living with PSP, family members and loved ones contributed through online polling, calling in by phone, and by submitting comments through the online portal. Many of the individuals living with PSP who participated in the meeting required prompts and reminders from their care partners to just "take a breath, slow down", highlighting PSP-specific challenges with speech and cognition. Many who attended the meeting were bereaved care partners for spouses or parents who had died from PSP.

The meeting video recording, meeting agenda, meeting discussion questions, meeting attendee demographics, online polling results, as well as additional written comments submitted through the online portal are available through the CurePSP EL-PFDD website, https://www.psp.org/pfdd.

The Progressive Supranuclear Palsy *Voice of the Patient* Report

The Progressive Supranuclear Palsy *Voice of the Patient* Report

This *Voice of the Patient* report is provided to all PSP community members and supporters including the FDA, other government agencies, regulatory authorities, medical product developers, academics, clinicians, and any other interested individuals. This report is organized to highlight insights that emerged at the February 6, 2026 EL-PFDD Meeting on PSP as well as the results of online polling. The content of this report may help inform the development of PSP-specific, clinically meaningful endpoints for current and future clinical trials, as well as encourage researchers and industry to investigate better treatment.

The input received from the February 6, 2026, EL-PFDD Meeting on PSP reflects a wide range of experiences of individuals living with PSP and their family members and care partners, however not all symptoms and impacts may be captured in this report. Patient and care partner comments were edited slightly for clarity and readability. The final report is available through the Cure PSP EL-PFDD website, https://www.psp.org/pfdd.

This Voice of the Patient report is dedicated to the members of the PSP community who we have already lost to this devastating disease.

"You start having balance problems. You think it's arthritis or something similar, but a doctor observes you, and thinks you might have a neurological problem like Parkinsons. You go to the neurologist, and he tells you that you have a neurological disease, that's not Parkinson's, and that is has no treatment or cure. You get referred to [Institute redacted], and they diagnose you with PSP. You do everything you're asked to do - physical exercise, occupational therapy, drug trial, and more. Despite your best efforts the disease progresses, and now, six years after diagnosis, you're paralyzed in bed, you can't speak, you can't eat on your own, you can't get out of bed, even to go to the bathroom, you can't communicate with your family or friends, and more. This is where my wife is now. No one wants or deserves this kind of life." **- Doug, PSP Care Partner**

Topic 1: **Living with PSP – Symptoms and Daily Impacts**

During the morning session of the EL-PFDD, those living with PSP and their care partners spoke candidly about their experience of living with PSP and how their symptoms and health effects impact daily life. They also spoke about their fears for a future living with PSP. Insights and poll results from this first session are summarized and illustrated with quotes from those living with PSP, their care partners and bereaved care partners of those who have passed. Results of the EL-PFDD meeting online polls can be found on the CurePSP EL-PFDD website, https://www.psp.org/pfdd.

Poll Questions 1 & 2 Results

Those living with PSP experience many different symptoms, with balance and mobility issues, choking or difficulty swallowing, and speech difficulties as the most troublesome. The interplay between individual symptoms makes everything more difficult.

People living with PSP and their care partners indicated that they or their loved one had experienced an average of **8.5 different** PSP-related health concerns. They were then asked to select their top three most troublesome PSP-related health concerns. Health concerns are listed in descending order of most troublesome and illustrated with patient quotes. Very few described these symptoms in isolation; most people experience many symptoms at once. As the discussion turned to daily life, it became clear that individual symptoms combined to create a powerful cumulative effect.

> *"I think it's hard for me to say how they all connect and how the underlying disease creates all these manifestations. But I think the cumulative impact on our loved ones is this loss of self and isolation."*- **Tom L., Bereaved PSP Care Partner**

Balance or mobility problems (falls)

Repeated and unexplained falling is often a first symptom of PSP, and 97% of those who participated in the polls reported experiencing this life-changing symptom. PSP causes some to appear to wobble when walking or have a "drunken sailor walk", and the PSP-related slowing of spontaneous movement can cause gait freezing and tiny shuffling steps which also leads to trips and falls. The lack of spontaneous movement makes it hard for those with PSP to catch themselves.

"I would say the most concerning symptom is falling. I fall several times every day. Typically, I fall forward onto my knees. I also lose my balance and fall backwards onto my butt. My knees are always banged up. It's a miracle I haven't broken anything."
- Chris H., Person with PSP

"She cannot walk on her own. Somebody has to support her and then she goes tiptoes. With that, walking becomes difficult and unless somebody holds onto her, she falls forward now. If we let her go, she falls backward. When we try to walk, she tends to fall forward because she's on her toes. So that's one issue we have."
- Sarath, PSP Care Partner

"At first, she was falling a lot, and they put her on some medication. Right now, her main issue is like trying to get up out of a chair, she'll go to get up, she'll fall back. And she'll do that two, three times before she can get herself to stand straight up. And if she tries to turn around, she'll go to fall. You got to watch that."
- Scott, PSP Care Partner

Choking or difficulty swallowing

Choking and difficulty swallowing are also experienced by most people living with PSP, and along with it, the risk of aspiration. Many spoke about how their loved one often coughs on their own saliva or due to food going down the wrong way. Some felt embarrassed about eating with others as a result, leading to increasing social isolation.

"Eating has become more difficult due to the swallowing and choking. Everything has to be cut up very small. John likes soft, small food better, it's a lot easier to swallow. When he drinks fluids, he chokes a lot of the time and someone has to remind him to be slow and pay attention to what he's doing since he forgets."
- Candice D., PSP Care Partner

"The most significant impacts by far were the inability to swallow—even her own saliva, the loss of her voice, and the profound effects on her executive functioning and decision-making abilities. As swallowing became unsafe, Laurie required a feeding tube placement, which fundamentally changed daily life and care."
- Mario, PSP Care Partner

"My mother has deteriorated significantly. She is now at the stage where it is very difficult for her to swallow. We were told that she is in the final stage of the disease, and I don't understand how they can say that with certainty when they don't even know enough about this disease." **- Catalena, PSP Care Partner**

Speech difficulties

Speech difficulties are experienced by 97% of those who participated in the poll and selected as the third most troubling symptom. Voices become softer or hoarse and harder to hear, words become harder to find, and pronunciation slows and becomes slurred. Every word takes more and more effort and eventually, many living with PSP are eventually unable to communicate with their friends and loved ones, intensifying feelings of isolation.

> *"The loss of social interaction is probably the most distressing for me due to impaired/slow speech. ... My wife says I have the same personality and sense of humor that I had pre-PSP, but the inability to communicate leads to frustration."*
> **- Paul, Person with PSP**
>
> With prompts from her husband, Phyllis shared her top health concerns.
> *"Definitely the lack of balance, and speech problems."*
> **- Phyllis, Person with PSP**
>
> *"One big problem we're having right now is with speech. She can just barely speak at all, and when she can speak, it's very hard to understand her. So it's a basic problem in communication. We just can't figure out what she's trying to say. It takes a lot of time. Sometimes, we can figure it out but it's very time-consuming, very frustrating for both of us because we just can't understand what she wants."*
> **- Stuart, PSP Care Partner**

Visual impairment

Blurred or double vision is often a first PSP symptom. Some have watery or teary eyes, while others experience extreme dryness leading to significant eye pain and cornea damage. Some have extreme light sensitivity, double vision, or struggle to keep their eyes open. Many living with PSP experience decreased eye movements when looking up or down, which can prevent them from seeing stairs, curbs or other objects and can contribute to falls.

> *"I can't look up. I can look down, but I have trouble looking up."*
> **- Lisa, Person with PSP**
>
> *"She has problems with vision, which is common with PSP. She's been back and forth to eye doctors and optometrists multiple times and got many different sets of glasses with many different prescriptions and nothing ever seems to help. But part of the problem is just communication. She can't really take an eye test very well because she can't speak so it's hard for the providers to treat her and give her the right prescription. And I'm not sure whether it would help even if she could, but that's part of the problem."*
> **- Stuart, PSP Care Partner**

> *"Javier had been having a constant teary eye problem. Then his eyes became dry due to reduced facial expression. He started having trouble following objects with his eyes. Turning his head became impossible."* **- Letty M., PSP Care Partner**

Urinary dysfunction and incontinence

Urinary dysfunction and incontinence can also be initial symptoms and are commonly dismissed simply as "aging". Some experience urgency and some need to urinate frequently.

> *"I began experiencing symptoms about a year and a half ago. I began with incontinence issues, which I understood at the time to be related to just age and I'm 67 years old."*
> **- Rob, Person Living with PSP**

> *"Janet's urinating urges, many are false alerts. The time between varies between 45 minutes, 120 minutes. A two-hour urinary pause, and we're grateful. Her frequent urinary trips combined with her balance issues are an extremely difficult aspect of her daily life and as her caregiver, mine."***- John H., Bereaved PSP Care Partner**

Cognitive or behavioral changes

Some experience cognitive changes including brain fog, memory challenges, loss of attention, processing issues, executive dysfunction, and cognitive decline. Some described their inability to plan what comes next. Care partners described a loss of impulse control leading to compulsive eating and a risk of choking or a need to stand up leading to increased fall risks. Some experience personality changes including **reduced emotional expressivity (facial masking)**, which was also a poll response option and includes apathy and emotional flatness. Some family members described irritability, frustration, anger, agitation and even anxiety and hallucinations. Some described how their loved one experienced a heartbreaking loss of a sense of self.

> During the EL-PFDD meeting, John relied on prompts from his wife Candice. *"A few of the problems I have are forgetting things, talking, walking, eating, and falling."*
> **- John D., Person with PSP**

> *"I can tell that Esther's memory and risk assessment capabilities are decreasing. I notice that Esther seems to walk and move as if with tunnel vision. She can't seem to visualize next steps or consequences in our physical world like before."*
> **- Jon H., PSP Care Partner**

> *"Knowing PSP caused his seemingly disinterested demeanor, lack of significant conversation, blank stare, and uncontrolled outbursts of words, made us understand his situation and helped us love him all the more."*
> **- Lexie, Bereaved PSP Care Partner**

Other PSP symptoms selected in the polls

These symptoms include the **loss of fine motor control**, which can lead to changes in handwriting and challenges with the ability to perform activities of daily living like self-care and dressing. **Muscle stiffness or involuntary movements** can include a loss of spontaneous movement, a loss of strength, hand clenching or shaking, frozen gait, and even alien hand syndrome. They also mentioned **sleep disturbances (insomnia or daytime sleepiness), and excessive salivation or drooling.**

> *"She also has frozen gait, which occurs at least once a day where she will go to get up out of a chair or go to move, to walk, and her brain tries to tell her legs to move and they just won't move. This is a very, very uncomfortable thing for Katie, especially in public places like restaurants where people don't understand what PSP is or how it affects someone like Katie. And she's frozen for a few minutes before she can move."*
> **- Pete L., PSP Care Partner**

> *"My husband then started with what doctors called the alien hand syndrome, which made his hand move in a circular motion on its own and caused constant pain. It became difficult to hold eating utensils, a toothbrush, or even write."* Eventually, *"his right arm lost movement and his hand closed up and became tightly clenched."*
> **- Letty M., PSP Care Partner**

PSP symptoms mentioned during the meeting and in submitted comments

Throughout the meeting, those living with PSP and their loved ones described some of the other PSP health concerns experienced, including fatigue, pain, teeth grinding, light headedness, depression, dermatitis, itching, constipation, fecal incontinence, loss of sense of smell, weight changes and even death. Although not a direct symptom, during the meeting discussion and in the submitted comments, patients living with PSP repeatedly mentioned **multiple hospitalizations and fall-related injuries** including dislocations, concussions, scalp lacerations, fractures and bruising impacted their day to day lives.

PSP Insight

PSP is progressive and unpredictable.

Many at the meeting compared PSP to a tsunami or a tidal wave, falling off a cliff, or a boulder rolling down the mountain. One described it as the process of literally dying in slow motion. With the presentation of each new symptom, families are required to constantly adapt and adjust to the "new normal" with unexpected challenges and losses, with no way to predict when the next decline will come. Families spoke about the emotional weight of these transitions, each symbolizing another loss of independence.

> *"PSP is relentless. It gradually took away her ability to walk, to speak, and eventually, express emotion. Watching my mother, a warm, joyful, faith-filled woman lose each of these abilities was devastating to our family."*
> **- Ariel, PSP Care Partner**

> *"The symptoms seemed to present sequentially and each symptom got worse. So I like to compare it to sort of a tidal wave or a tsunami. So one wave gets stronger and stronger, let's say, mobility, and then right behind it emerges a new wave and it builds. And then after a while you've got three or four of these waves building and it becomes a tsunami, which impacts your independence, your ability to cope with what you're facing, both for the patient and the care partner and others who are involved in care support."*
> **- Steve C., Bereaved PSP Care Partner**

> Tony spoke about PSP. *"It is very unpredictable. And what's most frightening is, if Phyllis gets tired or doesn't sleep well and the next day has really bad balance or can't speak very well, you think, 'Uh-oh, this is the next level.' So, you never really know when it's going to happen, but you know it's coming."* **- Tony C., PSP Care Partner**

PSP Insight

Some are very aware of their PSP-related decline and become prisoners of their own bodies.

The loss of intentional movement, speech and communication leave many people with PSP feeling increasingly trapped in their body, isolated, unable to communicate verbally, or even non-verbally when their awareness remains intact.

> *"My outgoing, funny, nature and travel-loving mom became a prisoner in her own body. She lost movement, balance, speech - her life."* **- Kathy, Bereaved PSP Care Partner**

> *"She doesn't speak, but when we talk to her and my dad and my sister and we make a funny comment, she laughs, so she understands. Sometimes she can say a phrase to my dad like 'I love you.'"* - **Catalena, PSP Care Partner**

> *"The most heartbreaking thing about PSP for families is knowing that the mind of the patient is still sharp, but the patient is unable to communicate. ... As horrendous as this was for my mother and our family to deal with, I cannot even begin to imagine the agony that my father experienced as his life slowly slipped away and he knew what was happening and that it would only get worse."* - **Lexie, Bereaved PSP Care Partner**

Poll Question 3 Results

Navigating the world becomes more challenging as PSP-related losses impact all activities of daily life.

Those living with PSP and their care partners selected their top three most important activities of daily life that they were not able to do or struggled with due to PSP. Many of those diagnosed with PSP are at an age when they were looking forward to the freedom of retirement. Instead, they face a future characterized by loss, as the disease steadily steals independence, movement and connection, leading to increased isolation.

The most important activities of daily life impacted by PSP are described descending order of most troublesome and illustrated with patient and care partner quotes, below.

Walking/mobility

Loss of walking and mobility was repeatedly identified as the symptom that most rapidly takes away independence, turning active, capable adults into people who must rely on walkers, wheelchairs, and constant assistance. The ability to get out of bed, move freely, leave the house, or participate in one's favorite activities are impacted.

> *"The mobility, in my opinion, is kind of what takes away the independence. ... It progressed from where she was kind of falling, ... to the point where she needed a cane. Then she could walk with a walker, and now she uses a walker, but I have to be with her. In other words, even with her just standing on a walker, she will fall if somebody's not holding onto her."*- **Jim G., PSP Care Partner**

> *"The extreme risk of falls restricts both of us to mostly spending our time at home. I have to be ready 24 hours a day to help Esther walk anywhere in the house, interrupting while I'm trying to work from my computer in another room, and even to help Esther into the bathroom in the middle of the night."*- **Jon H., PSP Care Partner**

> *"I can't jump or get out of a chair without extra effort. I would like to play a team sport again like basketball."* - **Kaye, Person with PSP**

Communicating

Communication challenges due to speech loss or cognitive changes add another profound layer of loss. Ordinary conversations with spouses, children, and friends grow increasingly difficult as speech becomes softer, slower or unintelligible. Communication challenges also hinder interactions with caregivers, impacting medical care and treatment.

> *"Speech and swallowing were huge things that very quickly overnight just declined. And with the speech, there really wasn't much we could do, unfortunately. And of all the symptoms, I think that affected my dad the most."*- **Kirrin H., Bereaved PSP Care Partner**

> *"I would say it's somewhat cognitive, but I think it's more just the mechanics of speech. It becomes so difficult to say something that it's easier to just leave it unsaid. And only things that really are necessary need to be said, 'bathroom', 'dinner', 'neck', 'pillow'. Single words that just are important in the moment and not kind of we're joking about a rug or a movie that we're watching on TNT."*- **Kelly F., PSP Care Partner**

> *"She can just barely speak at all, and when she can speak, it's very hard to understand her.... We just can't figure out what she's trying to say. It takes a lot of time. Sometimes, we can figure it out but it's very time-consuming, very frustrating for both of us because we just can't understand what she wants."*- **Stuart, PSP Care Partner**

Independent self-care (e.g, bathing, dressing, toileting)

Tasks such as cooking, gardening, household chores, dressing, bathing, driving, and even managing basic needs become impossible without help. The loss of independence can lead to depression and anger, and often the loss of dignity and a move to a care facility. Care partners play an enormous role in shouldering the care burden for PSP; this is described later in a separate section.

> *"One of the things that my wife loved to do was cook. Being able to focus down on a knife and chopping vegetables or cutting meats became such a challenge. ... That's one of those waves in the tsunami where my wife is not going to be able to cook anymore, and that's something that she loved to do."*- **Kelly F., PSP Care Partner**

> *"Something like getting to a shower, all of those things we take for granted and just being a human being day-to-day are a huge struggle, require a lot of planning. The kids need to get involved to get a shower, to get somebody who's strong enough."* - **Cara L., PSP Care Partner**

> *"She remained involved in dressing herself daily and her grooming and hygiene habits for as long as she could but progressively, her ability to do that declined and she needed help. And that deterioration unfolded over a roughly 12-month period of time going from being able to do all of those things, bathing herself, dressing herself, etc., to the point where she couldn't do any of those things by herself and needed assistance. And that certainly was another undermining of her feeling of independence."*- **Steve C., Bereaved PSP Care Partner**
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> *"The balance got me out of my home. ...I mean, I have fallen, and that is why I got out of the assisted living and I'm now in skilled nursing. ... I am living now in a skilled nursing facility, because I don't have family nearby."***-Lisa, Person with PSP**

Eating and drinking

During the EL-PFDD meeting, members of the PSP community shared the many ways that the disease interferes with eating and drinking. Many need to be reminded to chew, others eat uncontrollably, some grind their teeth and chew with their mouth open. Constant vigilance is required, as swallowing difficulties can lead to choking and aspiration. Swallowing issues also interfere with taking medications. Some are embarrassed to eat in front of others. Losing the ability to eat safely means losing connection, and a fundamental way of participating in family life and social circles.

> *"Her eating food has to be watched so she doesn't stuff her mouth, constant clearing of her throat, and spontaneous coughing out food or drink."*- **Dan, PSP Care Partner**
>
> *"My dad loved food and it was very hard for him to accept that he could no longer eat certain foods because of the risk of choking. He began drooling, sleeping more and more, and struggled to keep his eyes open at all times."*- **Ashley C., Bereaved PSP Care Partner**
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> *"Right now, the thing that concerns me the most, it's a swallow problem. And beyond just the risk of aspiration and choking, there's the loss of just about the only thing we can do socially anymore. We can't sing together, we can't travel, but at least we can find a good meal, we can find a favorite dessert, and that seems to be going away and just going to compound things even more."*- **Tony C., PSP Care Partner**

Other impacted activities of daily life selected in the polls

PSP impacts the ability to perform **fine motor tasks (e.g., writing, typing) and participate in recreational activities and events.** People spoke about no longer being able to cook, sew, play music, garden, help with chores, vote, walk the dog, get out in nature, travel, RVing, spend meaningful time with friends play golf or ride bikes. These only practical losses, as well as losses of joy and self-identity. **Maintaining social and family relationships** becomes harder as many gradually withdraw from the activities and relationships that once kept them connected to the world. **Driving or traveling independently,** often due to changes in eyesight and coordination, was an impact that affects independence and was mentioned frequently in the meeting. Many require assistance when getting in and out of vehicles. **Restful sleep** is impacted by sleep apnea, sleeping with their eyes half closed, sleeping most of the day, and requiring oxygen at night and upper body elevation. For many, the first PSP symptoms appear while they are still working, interfering with **managing school or work responsibilities** forcing them into early retirement.

> *"One of the first and most heartbreaking of his physical symptoms that he noticed was the loss of fine motor control in his hands. My dad had played guitar his entire life. It was his greatest passion and suddenly he could no longer move his fingers well enough to play. This loss was devastating to him."*- **Ashley C., Bereaved PSP Care Partner**

> *"My lived experience with this disease has been horrific. I can no longer swim, drive, walking my dog is challenging, I have to sell my bike which makes me very sad."* - **Tracy, Person with PSP**

> *"Running up and down the street with our grandson is gone. Hosting family events for 40+ on Christmas, Thanksgiving etc. is gone. Random 'come over for dinner' with 12+ family members is gone. Energy to party with family doesn't exist anymore."* - **Dan, PSP Care Partner**

PSP Insight

PSP leads to profound social isolation.

A key theme that emerged during the meeting was that of social isolation. Isolation affects the person living with the PSP as well as their care partners who no longer have the time or opportunities to meet with their friends.

> *"Socializing and keeping the world open is a huge problem. Phyllis still has a great deal to say. You just have to be patient enough to hear it. And people don't realize that. If neurologists can't recognize PSP, somebody at church on Sunday has no idea what she's suffering from and they treat her as if she weren't there. They speak to me when they're talking about her and she's sitting right there in the companion chair. So that's a huge problem."*- **Tony C., PSP Care Partner**

> *"Sadly only a few of her family call or visit now even after multiple asks on my part."* **- Dan, PSP Care Partner**
>
> *"The only living family member that I have is my sister who lives in NJ. I have gotten very isolated and ashamed of my symptoms."* **- Tracy, Person with PSP**

PSP Insight

Care partners shoulder an enormous PSP care burden.

A key theme that emerged during the meeting was the role of care partners in shouldering the enormous care burden of this disease. The responsibility can be physical and emotionally taxing, and some reported feeling helpless or aging overnight. Care partners help with mobility and fall prevention, coordination of appointments and therapy, manage communication and swallowing challenges, and adapt the home as needs change. During the meeting, many mentioned difficulties caused by size differences between the care partners and their loved ones. Some care partners also struggle with their own aging challenges. The disease impacts the whole family, including teenaged or adult children.

> *"I had to hire a caregiver to help me take care of him. He was 6 foot 4, I'm 5 foot 3. He kept falling backwards and I couldnt pick him up."* **- Deb, Bereaved PSP Care Partner**
>
> *"As the daughter of a mother with PSP, providing round-the-clock care with very little assistance has been overwhelming. My mom's condition makes it unsafe for her to live independently, yet she does not meet the criteria for nursing home placement, so she remains at home. ... Providing home care has exhausted all of my mother's savings, even though she lives in an in-law apartment with us. This has been the hardest thing I have had to maneuver, mentally, physically, and financially."***- Donna C., PSP Care Partner**
>
> *"He has become more homebound and isolated. Our dreams of volunteering in the community and travel, now that we were retired, were cut short. I say "we" because this disease affects the family, not just the person with the diagnosis. I am his care provider and it is close to a full time job."* **- Barbara, PSP Care Partner**

PSP Insight

PSP causes devastating changes to primary relationships, amplifying social isolation.

Changes to primary relationships as a result of PSP was one of the most heartbreaking themes that emerged during the EL-PFDD meeting. Care partners described the loss of camaraderie and true companionship. They spoke of how long marriages became more like parent-child relationships, and how even relationships with other family members and children profoundly changed.

> *"I think my PSP condition has affected my relationship with my husband because he's so worried about me that he often tells me that I've done something unsafe in a scolding way. It has affected my relationship with my daughter in a similar way."* **- Esther H., Person with PSP**
>
> *"Just losing that camaraderie with me, her caregiver and husband, that we don't have that rapport anymore. We don't have that interplay. We don't have those jokes that we share. And looking at the two couples that are on this panel, and seeing them smile at each other brings me back to those times when we would laugh together. And I just don't have that anymore. And God, I miss that. I miss that so much."***- Kelly F., PSP Care Partner**
>
> *"I just recently had to go to a wedding and I had to go solo. He is supposed to be my date forever, and this disease is stealing him from me and from our family. We are trying to make as many memories as possible while we can and while he can."* **- Candice D., PSP Care Partner**

Poll Question 4 Results

Those living with PSP experience many fears about further unpredictable symptoms and additional losses.

The top three worries of those affected by PSP include fears of what an unknown future living with a progressive neurodegenerative disease may bring. Care partners acknowledged how much fear they observed in their loved ones. Most of the fears reflect the symptoms or impacts already described previously. Fears of the future are described in descending order and illustrated with patient and caregiver quotes, below.

Life-threatening fall or choking episode

Families described constant fear of a catastrophic fall. Later in the disease, when patients get less independent, falling becomes less of an issue, however as swallowing difficulties worsen, the risk of choking and aspiration increases.

> *"It greatly worries me that Esther will one day, even momentarily, forget that she has PSP, with its massive and dangerous risk of falling. All it takes is a very tempting and seemingly normal step or two away from the chair and she could take the fall that ends her life or sends her to hospital and rehab with very low chance of walking again or recovery."*- **Jon H., PSP Care Partner**
>
> *"The fear of him choking is horrible."* - **Letty M., PSP Care Partner**

Losing ability to communicate

During the meeting many spoke about fears of losing the ability to communicate and socialize and the gradual closing off of their worlds. Some felt that a loss of communication was also a loss of self and personality.

> *"My dad was most fearful of losing his voice. ... He voiced several times how scared he was to lose his voice. He handled everything else like a champ, but losing the ability to speak was really scary to him."*- **Kirrin H., Bereaved PSP Care Partner**
>
> Jessica spoke of her fear, *"The future loss of being able to communicate with us. To not have my dad be able to talk to me."* - **Jessica, PSP Care Partner**

Loss of independence/inability for self-care and the burden being placed on caregivers and family

Many expressed a deep fear about becoming fully dependent on others for basic self-care, and about no longer being able to remain at home with a spouse or family member. The possibility of eventually needing institutional care was a big concern. Worry about the **burden placed on caregivers and family** reflects the insight about the heavy caregiver burden of PSP.

> Niki shared her fears. *"Bedridden, dependent on others ... not able to complete critical daily routine activities."* - **Niki, Person with PSP**
>
> *"I am frightened as to what will come in the future. Will I be able to take care of myself. Will I have to go into a nursing home. ... I hope that I will be able to handle the hurdles in front of me."* - **Brenda, Person with PSP**
>
> *"My wife is my only caretaker and sole provider, I worry about her and her ability to care for me as PSP begins to ravage my brain and my ability to think, talk, walk, and see."*
> - **Rob, Person with PSP**

Other fears selected in the polls

The other worries selected in the polls include **losing ability to swallow and safely eat, worsening depression, anxiety or emotional distress** and **cognitive or behavior changes affecting judgment or personality**. Worry about the **inability to participate in social or family activities** reflects the insight about the social isolation of PSP. Other worries include **losing the ability to walk or move independently, permanent vision impairment or loss, worsening tremors, stiffness, involuntary movements or coordination.**

> *"My dad, where under no circumstances, did he really want to ever go down the feeding tube route. … Well, he didn't have the feeding tube, because he passed away right before that."* **- Mana S., Bereaved PSP Care Partner**
>
> *"I'm also concerned about my cognition. I've already noticed some short-term memory loss and aphasia."* **- Esther H., Person with PSP**
>
> *"Very concerned about my eyesight. I'm an avid reader and I worry I won't be able to do much longer."***- Chris H., Person with PSP**

Other fears mentioned during the meeting or in submitted comments

Many with PSP and their care partners spoke about their **fear of their own death, fear of their loved one dying,** and of having already **passed PSP to their children or grandchildren.**

Topic 2: **Current and Future Approaches to PSP Treatment**

During the afternoon EL-PFDD session, those living with PSP discussed their experiences with the treatments and other PSP symptom-management approaches. They described treatment downsides and their preferences for future treatments. Insights and poll results are summarized and illustrated with quotes from those living with PSP as well as their care partners and loved ones. Results of the EL-PFDD meeting online polls can be found on the CurePSP EL-PFDD website, https://www.psp.org/pfdd.

PSP Insight

People with PSP often receive an initial misdiagnosis. Other diseases of aging make diagnosis and management even more difficult.

Many living with PSP experienced symptoms for several years before receiving a diagnosis. Sometimes patients and family members experience denial, and attribute falls and injuries to other causes such as poor footwear or bad lighting. Some felt that their symptoms were simply dismissed by their physicians as menopause or "aging". Misdiagnoses such as Parkinson's and myasthenia gravis are common. Comorbid conditions such as dementia and strokes can make diagnosis and management even more challenging.

> *"I noticed some changes in Patty. She, being fiercely independent and somewhat on the stubborn side, probably didn't want to recognize and acknowledge some of that."*
> **- Jim G., PSP Care Partner**

> *"My mother, Brenda, was officially diagnosed with Parkinson's disease in 2016, although our family sensed something was wrong long before then. ... Even with the Parkinson's diagnosis, something didn't fully make sense. A DaTscan came back abnormal, but inconclusive. Doctors continued to label it Parkinson's, but looking back, this was one of the earliest signs that my mother actually had PSP, progressive supranuclear palsy, a rare neurological condition frequently mistaken for Parkinson's in its early stages."* **- Ariel, PSP Care Partner**

> John's wife was initially diagnosed as being on the Parkinsonism spectrum. *"The more accurate PSP diagnosis was made two years later. We'll never get those two years back. Had we known from the outset that Janet had a terminal progressive neurological disease, we would've taken full advantage of her still active mobility. We would've traveled, we would've gone to Europe, knowing her mobility was progressively getting worse."***- John H., Bereaved PSP Care Partner**

Poll Question 5 Results

Current PSP treatment approaches are limited to symptom management. No approved therapies are available to address PSP disease manifestations or to slow disease progression.

Those living with PSP and their loved ones each selected an average of 3.8 medications that they had used to treat PSP-associated symptoms, with Parkinson's medications, ophthalmic treatments and sleep mediations as the top three selected. The medications selected in the polls are listed descending order and illustrated with patient quotes, below.

> *"Managing PSP required constant adaptation and an enormous amount of hands-on problem-solving."* - **Mario, PSP Care Partner**

Parkinson's medications (e.g., carbidopa, levodopa)

Most meeting participants reported trying Parkinson's disease medications. Sometimes carbidopa or levodopa were prescribed due to an initial Parkinson's misdiagnosis, other times they were intentionally prescribed to help with muscle stiffness and slowness. For many in the PSP community, these medications only provide partial relief or only work for a short time. Some also tried amantadine, but reported side effects of constipation, falls, delirium and visual hallucination.

> *"Her medication, carbidopa/levodopa, provided only partial relief, around 30 to 40%. When neurologists finally diagnosed my mom with PSP, it explained why traditional Parkinson's medication was never enough. Adjustments helped slightly, but the benefit was temporary and required frequent dosing throughout the day to maintain a basic function."* - **Ariel, PSP Care Partner**
>
> Amantadine has allowed Geri to reduce the amount of dopamine used. *"I think amantadine has helped me more than the carbidopa has helped me. ... I kept my eyes open more. I seem to be more alert and awake. It hasn't helped me with my falling."* - **Geri M., Person with PSP**
>
> *"I'm on carbidopa-levodopa, which helps with my falling and helps with my swallowing somewhat. ... Well, I hadn't fallen in quite some time and I had swallowing issues, but I hadn't gotten worse, so that was what helped with the carbidopa-levodopa. I'm on the smallest amount three times a day."* - **Lisa, Person with PSP**

Ophthalmic treatments for eye symptoms

Many mentioned trying different prescription and over-the-counter solutions for dry eyes including Refresh Eye Drops, "blood tears" or PRGF (plasma rich in growth factor) eye drops. Many mentioned multiple trips to see eye specialists and one admitted that this is where they have spent the most time and money. These eye solutions require frequent reapplication yet don't work very well or for very long.

> *"Notably, it took over a year and a long chain of specialist referrals to get an effective treatment for Heather's dry eyes. By the time we landed on PRGF eye drops or plasma rich in growth factor, aka blood tears and scleral lenses, Heather had endured significant eye pain and cornea damage. Although these treatments were our most significant victory to date, both are not covered by Medicare for PSP. This illustrates that the progression from first line to effective treatment is too often too slow for patients with PSP."* **- Pete E., PSP Care Partner**
>
> *"We have seen a local ophthalmologist and have made several trips to the [name redacted] Eye Clinic. We've tried pills and all sorts of eyedrops all to no avail. The specialists at the Eye Clinic prescribed various treatments, various eyedrops, nothing worked. The vision limitations and double visions have severely impacted Janet's life and limited her choices."***- John H., Bereaved PSP Care Partner**
>
> *"I have a lot of double vision, and I take Refresh Eye Drops. That's what the doctor gave me for my dry eyes. Doesn't seem to help much, but I am using it."* **- Geri M., Person with PSP**

Sleep medications

Sleep medications were the third most selected mediation in the poll. Some use melatonin, CBD and CPAP machines, while others tried off-label or experimental approaches.

> *"Sleep medications that are effective are CBD and lorazepam. Tylenol PM and melatonin were not effective for me."* **- Paul, Person with PSP**
>
> *"Her most recent difficulties have been sleep related. With the help of hospice, we're experimenting with various prescriptions to see which help. We've tried a combination of Baclofen, 20 milligrams, lorazepam, 0.5 milligrams. The lorazepam didn't help, and what currently does the trick is two 500 milligram Tylenol PMs and 20 milligrams of the Baclofen."***- John H., Bereaved PSP Care Partner**
>
> *"Better sleep helps with all symptoms. A CPAP machine and our current nightly cocktail of mirtazapine, trazodone, melatonin, Delta-8 and Delta-9 THC have kept Heather's sleep average at a reasonable level."* **- Pete E., PSP Care Partner**

Other medications selected in the polls

The long list of other medications selected in the polls include **anxiety or depression medications** (trazadone, Wellbutrin XL), **medications for urinary symptoms** (mirabegron, Gemtesa) and implants designed to control urinary flow, and internal catheter installation. Many also indicated that they use **pain management medications** (gabapentin) and **CBD or THC derivatives.**

> *"We use trazodone for anxiety, particularly in the afternoons and evenings. Heather now takes gabapentin for pain, and mirabegron for bladder control."* **- Pete E., PSP Care Partner**
>
> John's wife tried an implant to help with bladder control. *"The implant helped for some four weeks and then became a frustrating hindrance. Various prescriptions through hospice care have also been attempted, and again, no success. She currently wears a diaper to sleep at night and with two or three weeks of this writing, we will most likely request an internal catheter."* **- John H., Bereaved PSP Care Partner**

Medications and medical procedures mentioned during the meeting and in submitted comments

Families of those with PSP have tried almost anything to address the tsunami of PSP symptoms. They described medications for itching and dermatitis (gabapentin, ketoconazole shampoo and cream, pimecrolimus cream), Botox for muscle rigidity and pain, pacemaker installations, medications for hallucinations, and medications for oral secretions (scopolamine). Some tried more experimental treatments such as stem cell and platelet treatments, IV therapy with high dose vitamins and minerals, alpha lipoic acid, NAD+, glutathione and TrkB receptor agonists (7,8-Dihydroxyflavone).

Heartbreakingly, John described how his beloved wife Janet had obtained the medications for Medical Assistance in Dying (MAID).

> *"We have the California end of life meds in the house. She's in no pain, which makes end of life decisions more complicated. Her decision will be based on her creative abilities, which brings up what is most vital to her, her eyes. If her eyes functioned properly, she would paint, do collage, write, play Scrabble, and all the other related activities that monitoring technology would allow."* **- John H., Bereaved PSP Care Partner**

Investigational medicine in a clinical trial

In an effort to find symptomatic relief, a surprisingly large number of individuals living with PSP reported enrolling in clinical trials. Some were unsure if the trial medications were working, and others reported trials being discontinued due to lack of efficacy. Some reported being excluded from participation due to age, advanced disease, having a pacemaker or a rare PSP subtype.

> *"People ask us if the medications we received at our clinical trial are working. We don't know. It is hard to gauge where you should be with a disease you have never had. We don't have a good answer."* - **Raquel, PSP Care Partner**

> *"My husband was in a clinical trial which was stopped due to no change in patients. This was devastating, but we continued with hope of a new trial. We are still waiting six months later and beginning to lose hope. If given a choice of trying a trial drug or dying I think everyone would grasp for the gold ring. A chance to stop the progression of this horrible disease is worth every trial made available to the patient and family."*
> - **Tanya, PSP Care Partner**

> A clinical trial medication gave Linda three extra months of mobility and communication. *"During the second six months, ... everyone got the full dose of the drug. And in two weeks, it was like a miracle. ... All of a sudden, she was walking and she was talking and she was engaging. And it lasted for three months. And I'll tell you, those were the most precious three months of our life. ... It's still tough for me to talk about it, because it was such a special, special time. ... But after three months, it wore off, and then she died in August, but what a special time. It was like a gift."* - **Jack P., Bereaved PSP Care Partner**

Have not used medications

A small percentage of individuals indicated that they had not used any medications due to lack of efficacy or side effects.

> *"No medications now for the brain. Tried all Parkinson's meds. Most recently tried amantadine but stopped due to side affects. The only medications taken are for prostrate and blood pressure."* - **Betty, PSP Care Partner**

Poll Question 6 Results

As PSP progresses, more and more strategies and approaches to manage symptoms are required. Top approaches including physical therapy, exercise, structured physical activity, and speech therapy are important for helping to maintain abilities and also provide social support.

Members of the PSP community selected an average of 5.8 different treatment approaches that they or their loved one had used to help manage PSP symptoms. These included a wide range of approaches aimed at preserving function and dignity for as long as possible. Many emphasized that these non-medication approaches are often the most meaningful forms of treatment available, in some cases, helping to not only slow progression, but provide opportunities for socialization. Over time, treatment often shifted from attempts at functional improvement to measures aimed simply at safety and comfort. Of note, not one person selected Not applicable – not using anything to manage symptoms in the polls. Again, the treatment selected in the polls are listed descending order and illustrated with patient quotes, below.

Physical therapy, exercise or structured physical activity, occupational therapy

Physical therapy was the top approach selected by the polls, however comments about physical therapy and **exercise and structured physical activity**, and **occupational therapy** were so similar that these categories were combined. The PSP community described including working out, adaptive rock climbing, dancing, Tai Chi, boxing, walking, swimming, dance and Parkinson's-specific exercise programs. Many did physical therapy and other exercises many times a week. Benefits included improved proprioception, social connection, engagement, daily structure, and physical touch. Unfortunately, as the disease progressed, many described how their loved one no longer had the strength or coordination to continue these activities.

> *"I think emotionally, feeling like a person, having someone touch your body and have you raise your leg, I think that's helpful maybe as well for the emotional piece, the depression, that somebody is touching you, caring about you. Again, I'm not sure that it's actually helping in terms of the ability to walk, but I think it's hugely important."*- **Cara L., PSP Care Partner**
>
> Jack's wife danced with her physical therapist. *"He used to dance with her in the fitness center, and everybody else in the fitness center got a big charge out of watching Dr. Jake and Linda dance, but she loved it. ... I honestly think it helped slow the progression. It didn't stop the progression, but I believe it slowed the progression."* - **Jack P., Bereaved PSP Care Partner**
>
> *"I started speaking with a psychologist. I've been going to PT regularly and have improved my balance and I'm also seeing a speech therapist."* – **Brenda, Person with PSP**

Speech therapy

Many reported that speech therapy and related programs helped with speech and swallowing and made them feel less isolated. Several specifically described participating in the Parkinson Voice Project. While many reported success, sometimes the improvements are lost when the disease progresses.

> *"And I have had some PT and OT and speech, which have helped to ... I know the Voice Project for Parkinson, or Parkinson Voice Project. ... And I think it has helped a lot to not feel alone and to not feel isolated."* - **Lisa, Person with PSP**
>
> Stuart's wife had challenges with speaking clearly. *"We've worked with a speech therapist to try to figure out different ways of doing it, but so far haven't really come up with anything that works very consistently. I'm afraid it's going to even get worse. That's where we are right now."* - **Stuart, PSP Care Partner**

Mobility and positioning equipment

Mobility and positioning equipment becomes necessary for sitting, sleeping, bathing, toileting and transportation, and can help to preserve independence and dignity for as long as possible. During the meeting, many described how their loved one progressed from using a cane or a gait belt to a walker, or rollator or Sara Steady, to finally a wheelchair.

> *"We've used a broad array of mobility, speech, eating, bathing, toileting, sleeping, transport, and safety equipment. Heather now has a G-tube for nutrition and hydration, and a suction machine and percussion vest for breathing issues."* **- Pete E., PSP Care Partner**
>
> *"I progressed from a cane to a walker and I use a helmet now, because I fall a number of times and I hit my head. ... Now I use a helmet when I go out, and I don't care. I just will do anything I have to do to stay upright."* **- Geri M., Person with PSP**
>
> *"Between the gate belt, the rollator, and always a caregiver holding on, plus the wheelchair I use outside of the home, I manage to limit my falls to one to three times a month rather than two to three times a day."* **- Esther H., Person with PSP**

Home modifications

During the meeting many described a wide range of home modifications and safety equipment. Some have had to give up their homes and move to a safer or more appropriate accommodation. Some relocated to access better care.

> *"We adapted our home so that we could stay in our house. And yes, it costs money to do that, but a lot of things were simple. Like in the master bedroom, we tore up the wall-to-wall carpet and put in wood floor, so that a wheelchair could walk around on that. And we got other equipment, too. But those two things made a big difference."***- Jack P., Bereaved PSP Care Partner**
>
> *"My parents' house was fitted with handrails, bedrails, and any other safety measures for falls. He wore a fall monitor at all times."* **- Cheri, Bereaved PSP Care Partner**
>
> *"Equipment, we have purchased a platform lift in the garage to get him out of the house and into the wheelchair van. Our garage does not have enough room for a ramp, so we had to get a platform lift. We also have a wheelchair van. We got a transfer bench for the shower, a lift chair recliner, a SureHands wall-mounted lift for the bedroom to get him out of bed and into a chair, and U-Step 2 rollator. There is one additional piece of equipment that we need, and it's a battery-operated sit-to-stand lift assist as his leg strength is weakening and therefore, the need for the lift is increasing."* **- Dawn R., PSP Care Partner**

Swallowing management strategies

Maintaining the ability to swallow and eat independently involves the support of speech and swallowing therapists who can promote effective swallow protocols and neuromuscular electrical stimulation. Other strategies can include adaptive cutlery, raised plates, sippy cups and adaptive drinking glasses. As swallowing becomes more challenging, other strategies are added including special diets, blending food into purees, the use of thickening agents for liquids to prevent choking, and crushing medications into smoothies. Later, feeding tubes are necessary as well as suction machines to prevent aspiration.

> *"Eventually, I had to move to a plastic cup because if I gave her a glass cup, she would bite down on the glass. The glass could potentially break. Same with a spoon. I had to move to a plastic spoon because she was biting down on this metal spoon just from a safety perspective. I don't think she likes that because then she feels infantile, but it's a safety precaution."* **- Kelly F., PSP Care Partner**
>
> *"As swallowing became unsafe, Lori required a feeding tube placement, which fundamentally changed daily life and care, and then they had to resort to using a suction machine to remove oral secretion."* **– Mario, PSP Care Partner**

Other PSP symptom-management approaches selected in the polls

Some of the other treatment approaches selected in the polls include **nutritional support**, or "intensive nutrition", which becomes very important, especially closer to the end of life. **Vision-supportive care and interventions** include scleral lenses, prisms, dark glasses, covering one eye to counter double vision, enlarged fonts on computers and books, audio books. Many described **communication aids** including American Sign Language, letter board, SpeechVive (which increases voice volume), text-to-speech technology, eye gaze, iPad, alternative and augmentative communication (AAC) devices, a synthetic voice. Some of these take significant effort to implement and only help while those living with PSP retain their abilities.

> *"His last few weeks /months of sustenance became various liquids frozen into old "ice pop/freeze pop" popsicle bags. He could not chew or swallow liquids and had to slowly suck on these in order to have any liquids or nutrition of the smallest type."* **- Lexie, Bereaved PSP Care Partner**
>
> *"I have prisms in my glasses now. It doesn't help me that much, but it helps a little bit. And I can't really see what I'm eating, because I look down and I can't really … Everything is double vision when I look down. So, that is affecting me."***- Geri M., Person with PSP**
>
> *"When he lost his ability to speak, none of his voice banking or assistive devices could he used."* **- Lisa H., Bereaved PSP Care Partner**

PSP symptom-management approaches mentioned during the meeting and in submitted comments

Throughout the meeting, those living with PSP and their loved ones described the many other things that they tried to help manage their PSP symptoms. Socialization and support groups were mentioned most often, for the person with PSP as well as their care partners. Other approaches include mentioned working with a psychologist, listening to classical music, deep tissue massage therapy, percussion vest for breathing issues, hyperbaric chambers, maintaining a positive attitude transcranial direct current stimulation (a non-invasive safe brain stimulation), infrared helmet biofeedback, vibration therapy, breathwork, 40hz sound and light therapy, lasers, low energy neurofeedback, reiki, Kloud, magnets.

> *"I have registered with the hospice, who support us with various activities."* - **Mervin, PSP Care Partner**
>
> *"People come over and do jigsaw puzzles just to show caring. Of course, the PSP patient can't do the jigsaw puzzle but feeling that sense of community, all of those pieces I think are hugely important at every stage but particularly at this stage."* - **Cara L., PSP Care Partner**
>
> *"We figured that's the best medicine for her right now, is to have that cup of coffee and somebody comes over in 10 minutes."* - **Richard M., PSP Care Partner**

Poll Questions 7 & 8 Results

Medications and treatment approaches do not stop or slow PSP disease progression and only work very little or somewhat for most.

Those living with PSP and their loved ones selected the top three drawbacks of their or their loved ones' current treatment approaches. The top drawbacks selected in the polls were, "do not stop or slow disease progression", "not very effective at treating target symptoms", and "only treat some not all symptoms". This was consistent with how they described how well their current treatment controls their or their loved one's symptoms overall. While a small minority reported that their treatment works to a great extent (12%), the majority of poll respondents reported that their treatment only works "somewhat" (44%) or "very little" (44%). Not one person indicated that their treatment works "not at all" or "not applicable – not using anything". PSP treatment drawbacks selected in the polls are listed descending order and illustrated with patient quotes, below.

Do not stop or slow disease progression

The fact that treatments **do not stop or slow disease progression**, was not only the main drawback identified in the poll but was a key theme of the entire meeting. Related poll responses included n**ot very effective at treating target symptoms, only treats some, not all, symptom(s), loss of effectiveness over time.**

"I have found that many of medications I have tried to alleviate the gait/balance/ stiffness issues (CD-LD, amantadine, baclofen) have been subtle at best to not working at all. I have titrated them up and down over the past ~6 years as well as different combinations with minimal impact." **- Paul, Person with PSP**

"Katie and I don't really feel there's a lot of options right now when it comes to treatments for her symptoms, but we currently are focused on in-home options such as physical, speech, and occupational therapy." **- Pete L., PSP Care Partner**

"She was misdiagnosed with Parkinson's, which seems to be really,really prevalent. They put her on carbidopa-levodopa. It made her feel worse. And that was the tipoff that something else was going on." **- Jack P., Bereaved PSP Care Partner**

Time-intensive and exhausting daily routines, limited availability or accessibility

PSP has a heavy treatment burden. Therapies leave patients exhausted and the amount of time that other family members are required to spend facilitating treatment is extensive. Distance often limits the availability and accessibility of treatment.

"Finding and implementing treatments for the ever-changing symptoms has been a major challenge. ... We've seen numerous healthcare providers, including multiple neurologists; physical, occupational, and speech therapists, pelvic floor specialists, ENTs, neuro - ophthalmologists, cornea specialists, wheelchair specialists, and more." **- Pete E., PSP Care Partner**

"The worst experience though for me was taking her to neurology appointments 90 miles from our home only to struggle with the lack of ADA [American Disability Act] accessibility of the clinic. Once we struggled to get in narrow doors that I would literally have to prop open with my foot as I used the rest of my body to wheel her through the door, I would get in to the doctor's office only to find more narrow doors, cramped exam rooms, and a poorly designed bathroom that I had to take the garbage can out of the bathroom just to make room for her wheelchair." **– Jackie, Bereaved PSP Care Partner**

"None of these treatments treat symptoms particularly well. And the downsides are that PT, OT, and speech therapy tires me out." **- Lesliel, Person with PSP**

High cost or co-pay, not covered by insurance

Many described having to pay out of pocket for essential as well as more experimental treatment approaches.

> *"Speech therapy early on helped, but as PSP advanced, because it was so few therapists that understood the disease, she often wasn't approved for ongoing sessions, even when we saw a clear benefit."* - **Ariel, PSP Care Partner**

> *"He's also gotten TruDOSE plasma-rich platelet treatments. He had a low platelet count and would bruise horribly after each fall. These treatments cost about $1,500 and are not covered by insurance."* - **Dawn R., PSP Care Partner**

Side effects

Some described trying medications only to stop them because the side effects outweighed the limited benefits.

> *"Tried all Parkinsons meds. Most recently tried Amantadine but stopped due to side affects. ... Not certain of any medications helping symptoms due to opposing the side affects and then discontinuing. ... Side effect of thrashing and vocal disturbing dreams and electrical(?) involuntary shudder twitches in neck and head causing a squeaky voice and discomfort."* - **Betty, PSP Care Partner**

> *"The drugs are not effective and cause terrible side effects. We had speech therapy and physical therapy several days a week for over two years with little if any progress and actually just the opposite."* - **Mario, PSP Care Partner**

Poll Question 9 Results

Short of a complete cure, the PSP community wants a medication to slow or stop disease progression.

Those with PSP as well as their care partners indicated the top three specific things they would look for in an ideal treatment for PSP, short of a complete cure. While slowing or stopping disease progression was the top poll result, they also highlighted specific skills or abilities that they wanted to improve or maintain for as long as possible including the ability to swallow, communicate, move, balance, see, and remain independent. The top treatment goals selected in the polls are listed descending order and illustrated with patient quotes, below.

Slow or stop disease progression

Slowing or stopping disease progression was the top goal of an ideal future PSP treatment. Some mentioned how this would help to preserve an individual's sense of self and a family's financial well-being.

> *"An ideal treatment for PSP would be to slow it down."* – **Kaye, Person with PSP**
>
> *"I am the care giver for my wife who was diagnosed in Aug 2024. Unfortunately she exhibits all the symptoms possible: speech, vision, balance and weakness. A treatment to slow down or reverse this disease would be a blessing."* - **Peter D., PSP Care Partner**
>
> *"The thing that really struck me in Lynn's progression was the loss of self and apathy, emotional flatness, and then cognitive decline. And it's just so heartbreaking to see that loss of self, it's even hard to say it. But I think any treatment that is addressing the underlying mechanisms of this disease and that can prolong the self that we all loved and we're losing slowly."* - **Tom L., Bereaved PSP Care Partner**

Preserve or improve ability to swallow and eat safely and maintain the ability to communicate

Those living with PSP and their care partners want a treatment to preserve, improve or maintain the ability to swallow, eat safely and communicate.

> *"Aside from a cure, I'd like to find a way to slow the disease, especially its impact on eating and communication."* - **Lisa H., Bereaved PSP Care Partner**
>
> *"In the final months of his life, I asked him what would make him happiest. His answer was simple: to walk and talk again. To communicate that wish, he had to slowly point to letters on an alphabet board."* - **Alice M.. Bereaved PS Care Partner**
>
> *"An ideal treatment would be a medication that could slow the progression of this disease, especially for swallowing and speaking. The choking kills a social life, our social life, because it scares everyone around when he chokes when he eats."* - **Dawn R., PSP Care Partner**

Improved mobility, and reduction in falls/improvement in balance

Other top poll responses include improved mobility, reduction in falls and improvement in balance.

> *"I would like to see some medicines out there maybe to help with the falling. That's one of the biggest issues that I have, dealing with my wife with PSP. She's been on different medications, and to me, she's kind of one of the lucky ones, she's been holding her own for a while. It's been quite a journey the last couple of years."* - **Scott, PSP Care Partner**
>
> *"I don't want to fall anymore, I've fallen enough."* - **Geri M., Person with PSP**

Other goals for an ideal PSP treatment selected in the polls

Other goals selected in the polls include **preserving vision, preserve independence in daily activities, reduced care partner burden, address multiple symptoms simultaneously** including medications to help with cognition.

> *"Drugs to help with brain issues. To help balance and walking."* - **Gordon, Person with PSP**
>
> *"Independence and the ability to maintain independence is such a critical part to self-dignity and the shock of how fast things are progressing. ... Early solutions to address or help continue that independence, I think is a key aspect. And I know that can mean a lot of things. But just daily activities of being able to live the way you know how to live versus being dependent on everybody and having that shift so quickly."*
> - **Mana S., Bereaved PSP Care Partner**

Other goals for an ideal PSP treatment as well as other needs of the PSP community mentioned during the meeting and in submitted comments

During the meeting and in submitted comments people with PSP identified other treatment goals and other urgent PSP community needs. PSP patients would like **therapies that addressed the underlying cause of PSP** rather than just its symptoms. Some would like **more navigational support** to help families prepare for the PSP journey. They mentioned needing **easier to swallow medications**, for a population where swallowing difficulties are a major issue. Some would like a **faster and more accurate PSP diagnoses**.

> *"Help the brain to clean up the tau, help the brain to develop new neurons and network, stabilize body function such as balance, minimize stiffness. Help to swallow, stronger voice. Explaination to how PSP is developed/is contracted."* - **Carolina, PSP Care Partner**
>
> *"Because PSP is unknown, resources are not allocated to educate, identify, and train the medical field. ... Proper PSP funding, education, care, and awareness WILL make a significant impact in the lives of patients, caretakers, and the entire medical community."*- **Marguerite, Bereaved PSP Care Partner**

PSP Insight

The PSP community would like more clinical trials and discussed factors that would be important in deciding whether to participate in a new trial.

The PSP community would like clinical trials to be more inclusive. PSP clinical trials need to include people all along the PSP journey from those who were very recently diagnosed to those with advanced disease, people of all ages, and all PSP subtypes including the rare versions. As PSP primarily affects older adults, the clinical trials must also include those with comorbid conditions.

While many would participate in a trial no matter what the outcomes, others may hope to see some benefit from participation, or at minimum feel reassured that participation is unlikely to cause harm, when deciding whether to continue. Some hope for continued access to any medications after the trial. Some want to know how participation might affect quality of life for both the patient and their caregiver, including side effects. Other PSP-specific considerations include the need for localized clinical trial sites, to allow those who are care partner-dependent, who struggle with mobility and communication, or who can't travel for long distances to participate. Some also asked for reimbursement for travel, accommodation and food during the trial.

> Geri emphasized how trials including those early in the PSP journey is important. *"I would like to be a trial because of the fact that I'm new at this, I have very few of the symptoms that everybody else has been talking about, but I don't want to get that far, I don't want to have those symptoms either."* - **Geri M., Person with PSP**
>
> *"It would be helpful if clinical trials for medication included patients further along in the disease process. ... A problem with participation in clinical trials us the toll it takes on a PSP patient/caregiver having to travel and the hours involved. They get tired / fatigued. Maybe allowing testing / scans etc to be done at sites closer to home would enable more people to participate."* - **Cindy, PSP Care Partner**
>
> *"There are no barriers as we would love to participate in a trial."* - **Mervyn, PSP Care Partner**
>
> *"We'd do anything to participate in a research trial to help find drugs for PSP symptoms, so others don't have so suffer through this heartbreaking disease."* - **Jessica, PSP Care Partner**
>
> *"I would gladly participate in any clinical trial that would help anyone besides me."* - **Tracy, Person with PSP**

"Side effects would be a top consideration - Bob did not do well with many medications." **- Julie, PSP Care Partner**

"To be part of clinical trial, it would depend on the location. If it was accessible by car would be ideal." **- Kaye, Person with PSP**

Niki shared her clinical trial considerations. *"Impact the root cause (Tau protein), location, cost, duration, who is conducting the research."* - **Niki, Person with PSP**

"Type of medication and possible effects, low placebo ratio, possibility to continue to take the medication if proven to be effective. Location and trial program management. Close follow up and overview of the impact of the treatment." - **Carolina, PSP Care Partner**

Acknowledgments

CurePSP acknowledges the many important organizations and individuals who contributed to the success of the Externally-Led Patient Focused Drug Development (EL-PFDD) meeting on Supranuclear Palsy (PSP) and to the publication of this PSP Voice of the Patient Report.

Thank you to the FDA staff from who took the time to attend our February 6, 2026, EL-PFDD meeting and who read this report. Thank you to Dr. Michelle Campbell, Associate Director for Stakeholder Engagement and Clinical Outcomes for the Office of Neuroscience in the Center for Drug Evaluation and Research for providing a welcome from the FDA. Thank you to Will Lewallen from the FDA's PFDD staff who guided us through this process over the many months of planning.

Thank you to our esteemed clinical experts, Dr. Jori Fleisher, director of the CurePSP Center of Care at Rush University - Medical Center, and Dr. Anne-Marie Wills MD, MPH, director of the CurePSP Center of Care at Massachusetts General Hospital for so generously sharing their vast clinical and research expertise during our meeting.

Thank you to our generous industry sponsors: Ferrer; a Spanish-based pharma company focusing on rare disease; GemVax & KAEL, a Korean-based biotech company; and Novartis, a global pharmaceutical company. Without your support, our EL-PFDD meeting would not have been possible.

Thank you to all the representatives from professional organizations, pharmaceutical companies, federal agencies, and clinical and research centers from all around the globe for attending our meeting and reading this report. We express our appreciation to the investigators and clinicians who have dedicated their careers to improving the lives of people living with PSP and who are moving us closer to better care, stronger evidence, and more effective clinical trials.

Thank you to James E. Valentine, JD, MHS and Sarah L. Wicks, JD, MPH from HPM for their invaluable assistance in planning and moderating our EL-PFDD meeting and to the Dudley Digital Works media team for their production and execution of this meeting. We also extend our deep gratitude to our CurePSP staff, our board and our volunteers who spent many hours in preparing for the EL-PFDD meeting. A special thanks to CurePSP colleagues across our small but mighty team including Jessica, Courtney, Rich, and Sabrina.

Finally, and most importantly, we are grateful to members of our community whose lives were directly impacted by PSP and chose to let their voices be part of our meeting and this report. Thank you to our many speakers, panelists and callers for openly sharing your lived experiences of what it is like to live with PSP. We are grateful to have had this opportunity to ensure that patient and caregiver's perspectives will be considered in the drug development and regulatory process. Our hope is that this meeting will help accelerate momentum, encouraging your research, sharpening what meaningful benefit looks like to patients and care partners, and ultimately leading to successful new treatment options for PSP.

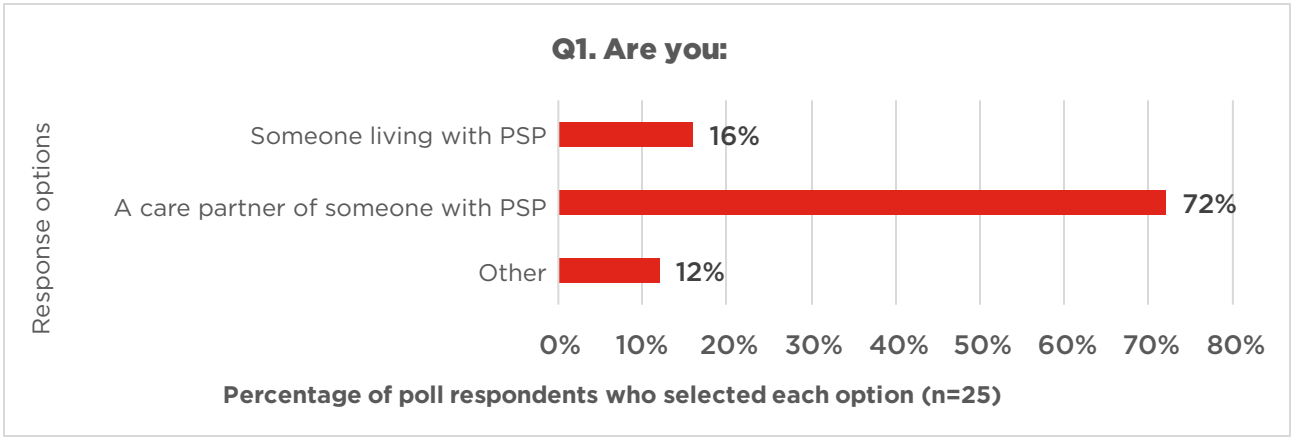
Progressive Supranuclear Palsy
Poll Results

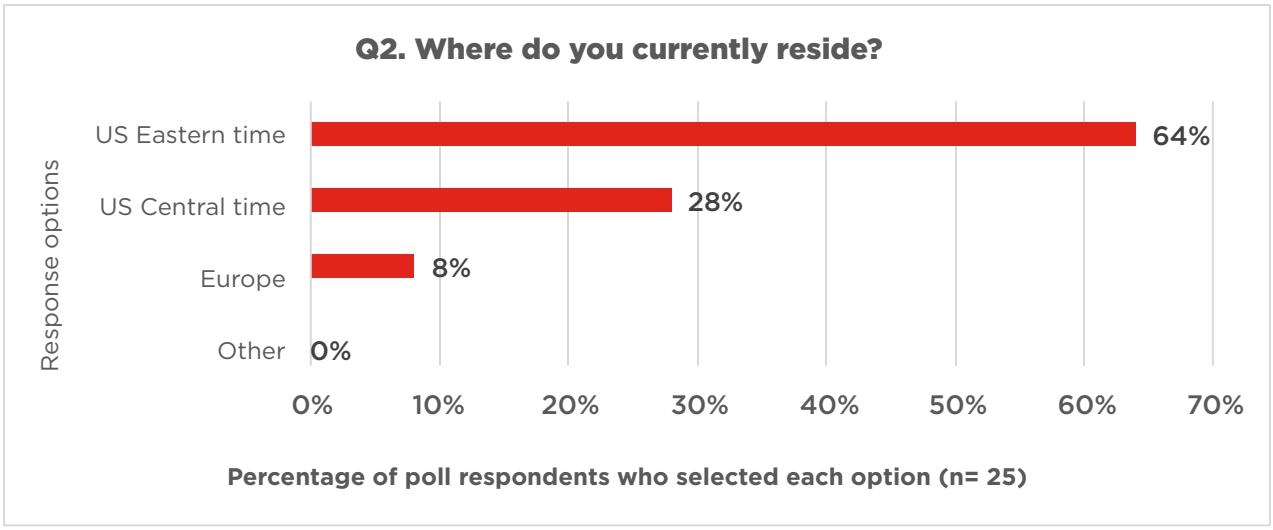
Meeting Date: February 6, 2026; Report Date: June 24, 2026

CurePSP hosted the Externally-Led Patient Focused Drug Development (EL-PFDD) Meeting on Progressive Supranuclear Palsy (PSP) on February 6, 2026. During the meeting those living with progressive supranuclear palsy, family members and loved ones contributed through online polling, the results of which are presented in this document. The PSP *Voice of the Patient* report is available online at https://www.psp.org/pfdd along with this document.

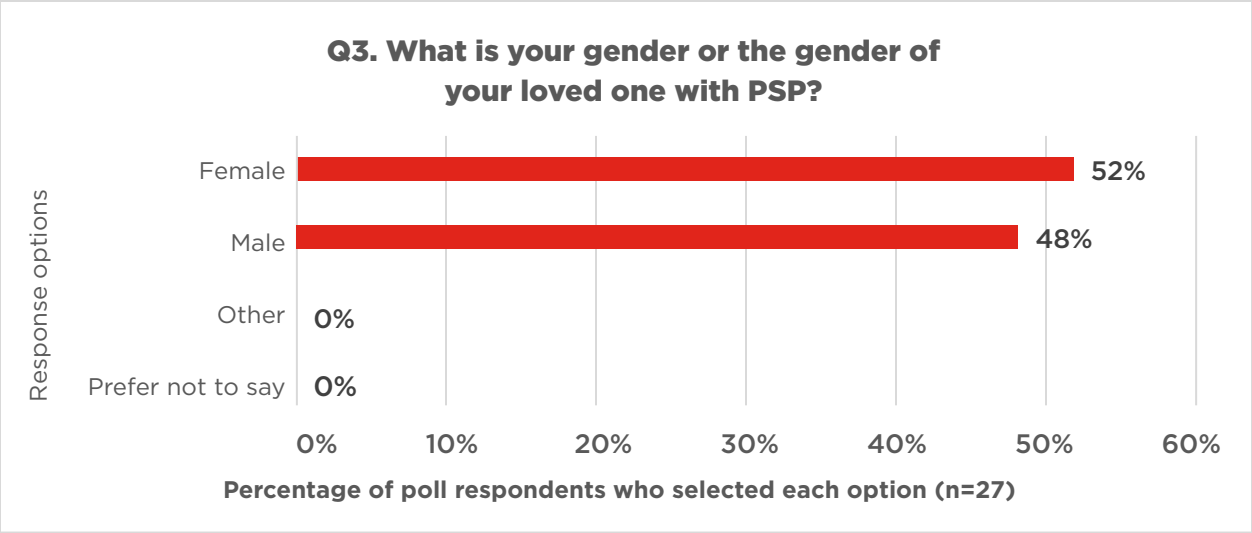
Demographic questions

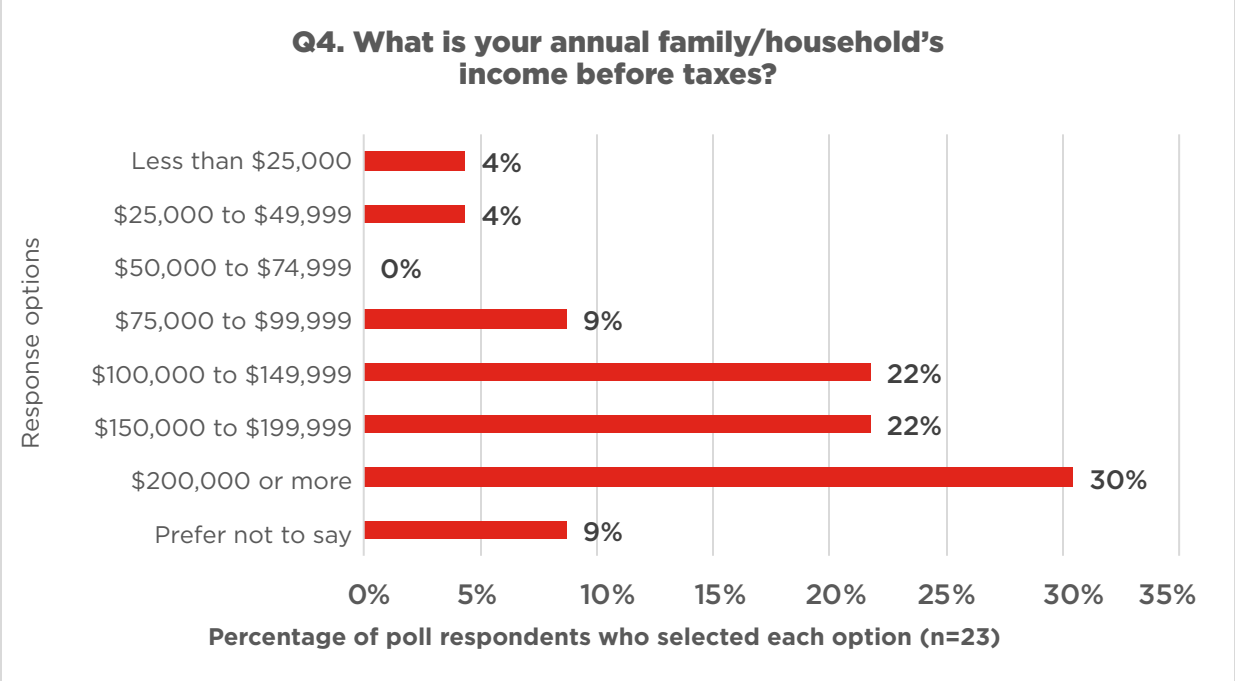
These graphs include the responses from those living with PSP caregivers and family members who chose to participate in online polling at the EL-PFDD meeting. Bereaved caregivers and family members were invited to participate, answering on behalf of their loved one who had passed away. The number of individuals who responded to each polling question is shown below the X axis (n=x). The responses for these polling questions are not considered scientific data but are intended to complement the patient comments made during and after the meeting. Note that meeting demographics were dynamic and may have changed as more individuals joined the meeting.

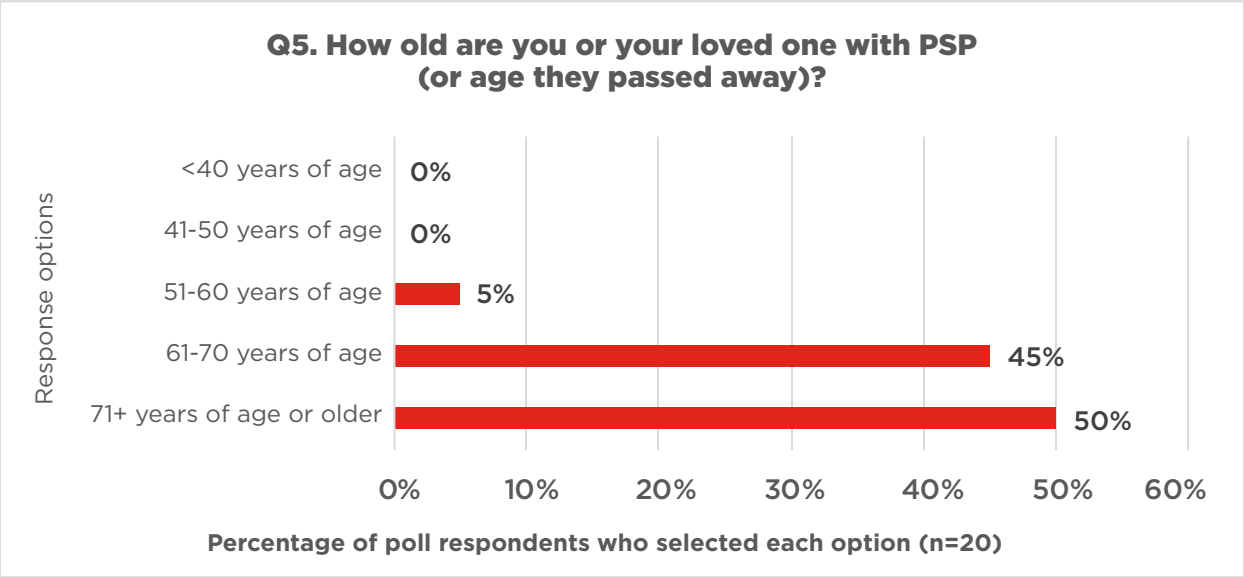




At the time of demographic polling there were no participants from US Mountain, Pacific Alaska or Hawaiian time zones, Mexico, Canada, Asia or the Middle East. Participants from these states and countries may have joined during the course of the meeting.



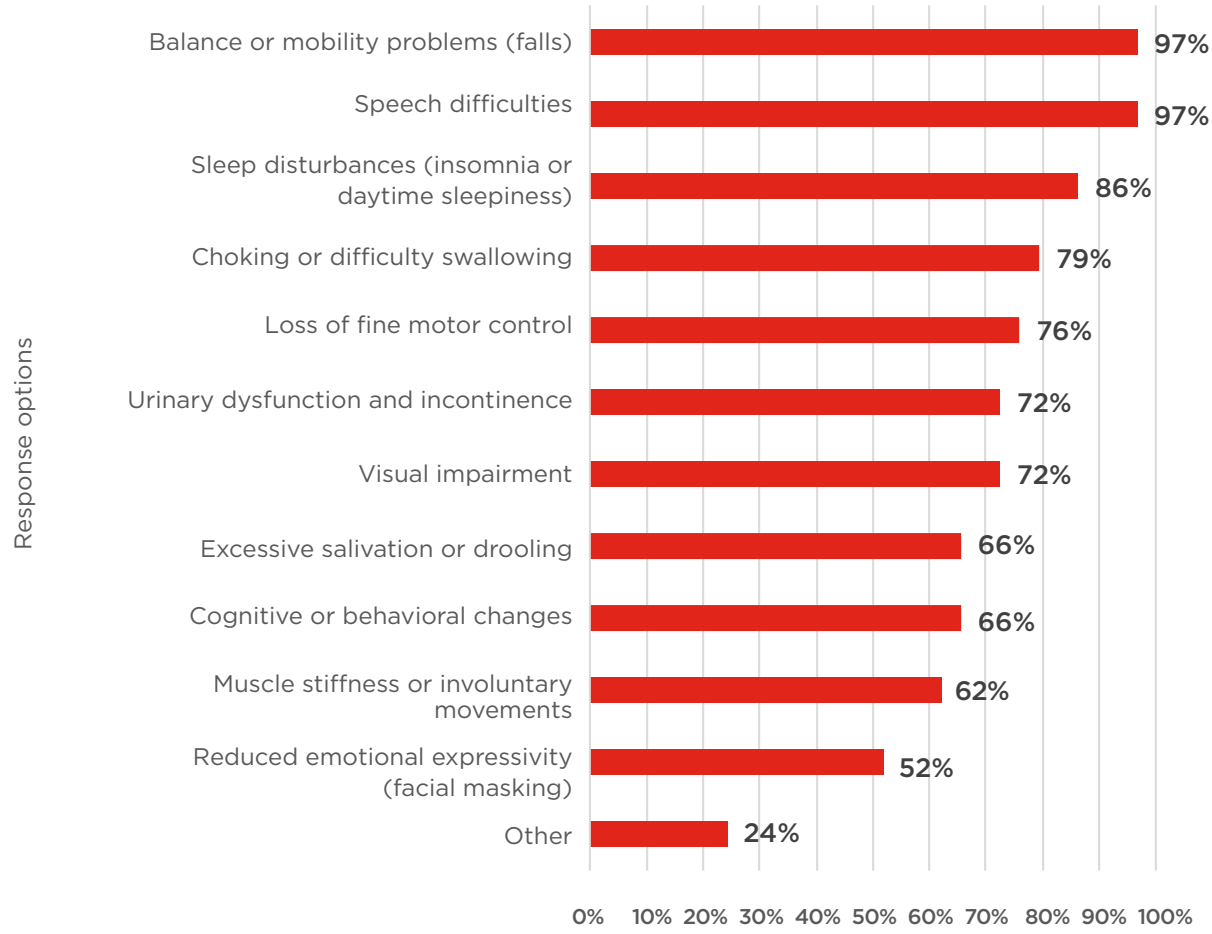



Q5. How old are you or your loved one with PSP (or age they passed away)?
Response options
<40 years of age
41-50 years of age
51-60 years of age
61-70 years of age
71+ years of age or older
0%
0%
5%
45%
50%
0%
10%
20%
30%
40%
50%
60%
Percentage of poll respondents who selected each option (n=20)

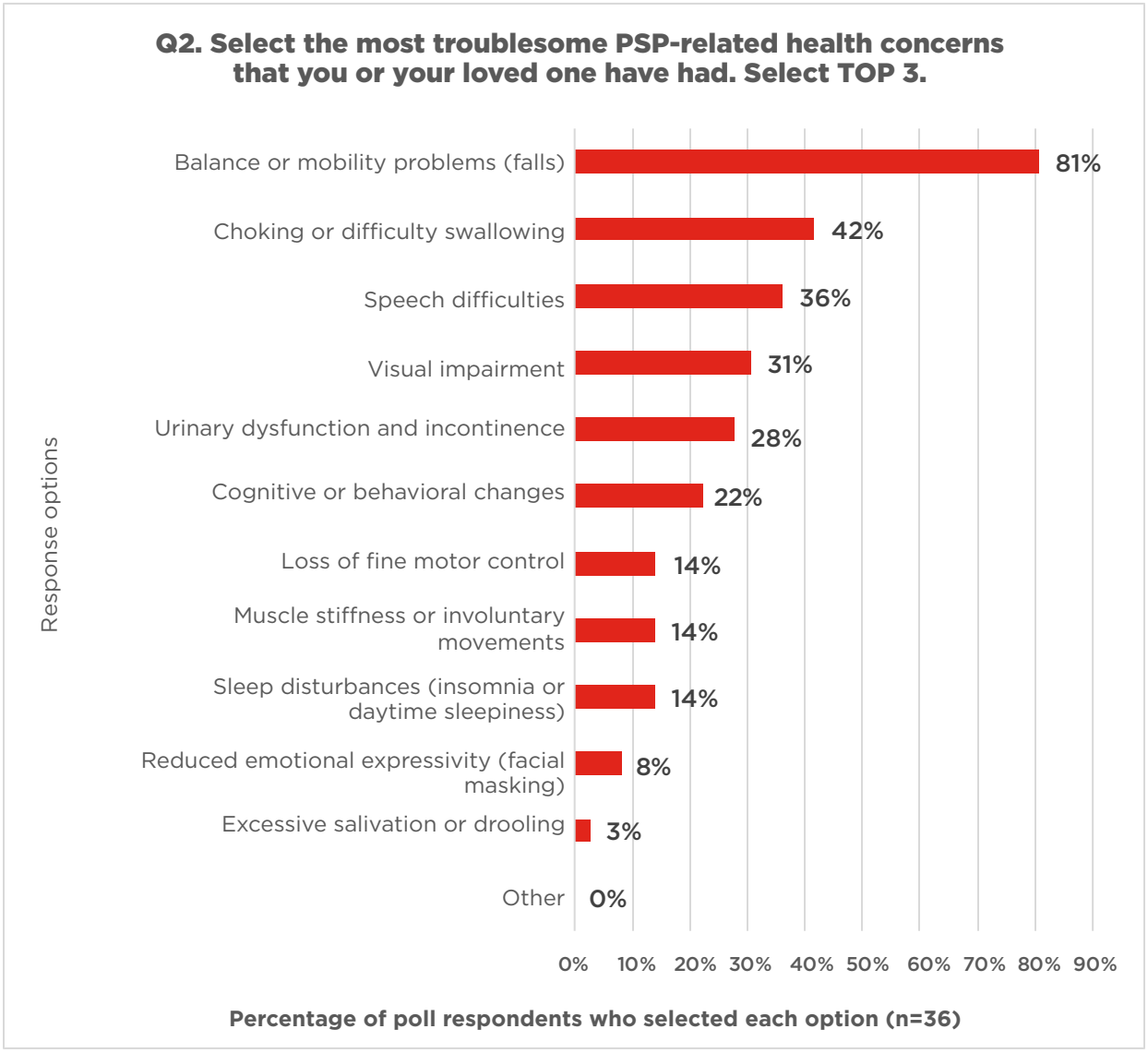
Poll Responses to Topic 1: **Progressive Supranuclear Palsy Symptoms and Daily Impact**

These graphs include the responses from those living with PSP, caregivers and family members who chose to participate in online polling at the EL-PFDD meeting. Bereaved caregivers and family members were invited to participate, answering on behalf of their loved one who had passed away. The number of individuals who responded to each polling question is shown below the X axis (n =x). For polls where the respondents could select more than one response, the sum of the responses is greater than 100%. While the response rate for these polling questions is not considered scientific data, it provides a snapshot of those who participated in the EL-PFDD meeting on PSP.

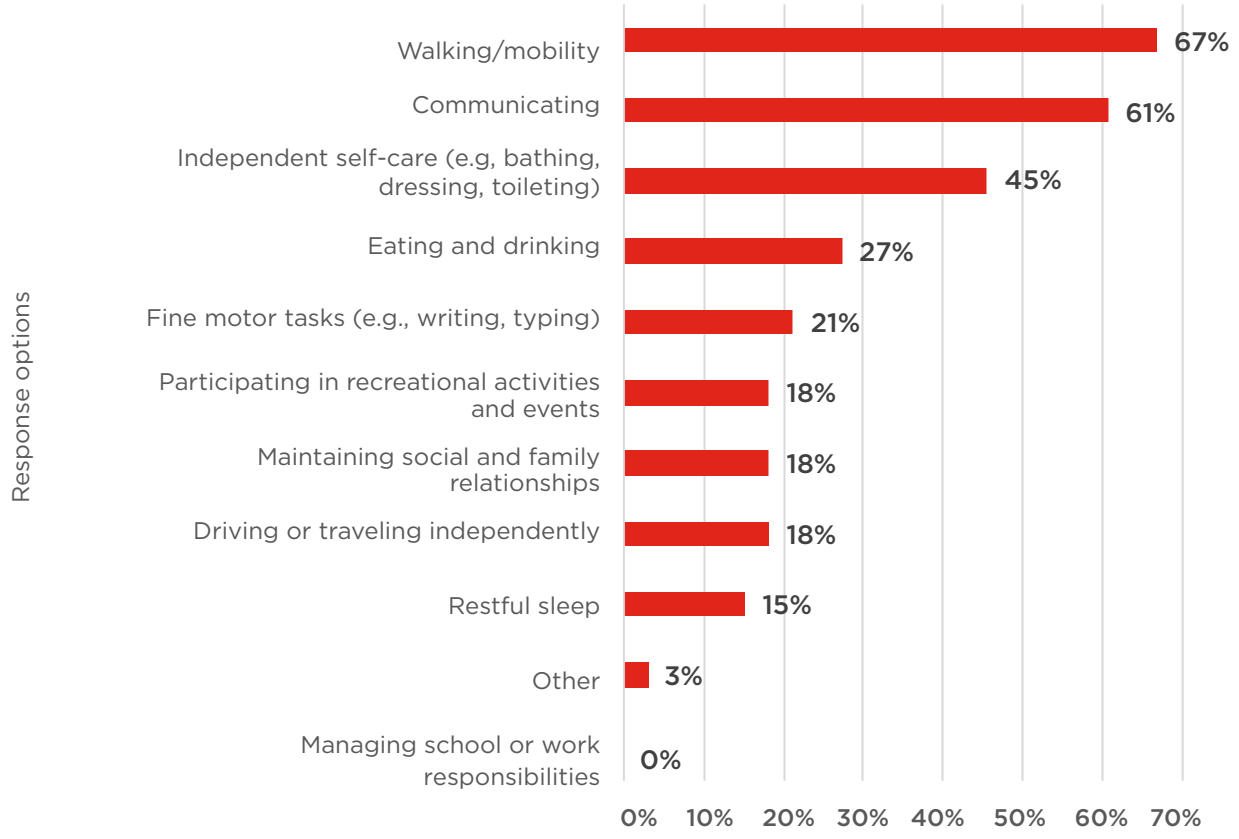
Q1. Which of the following PSP related health concerns have you or your loved one ever had? Select ALL that apply.



Percentage of poll respondents who selected each option (n=29)
Each respondent selected an average of 8.5 response options

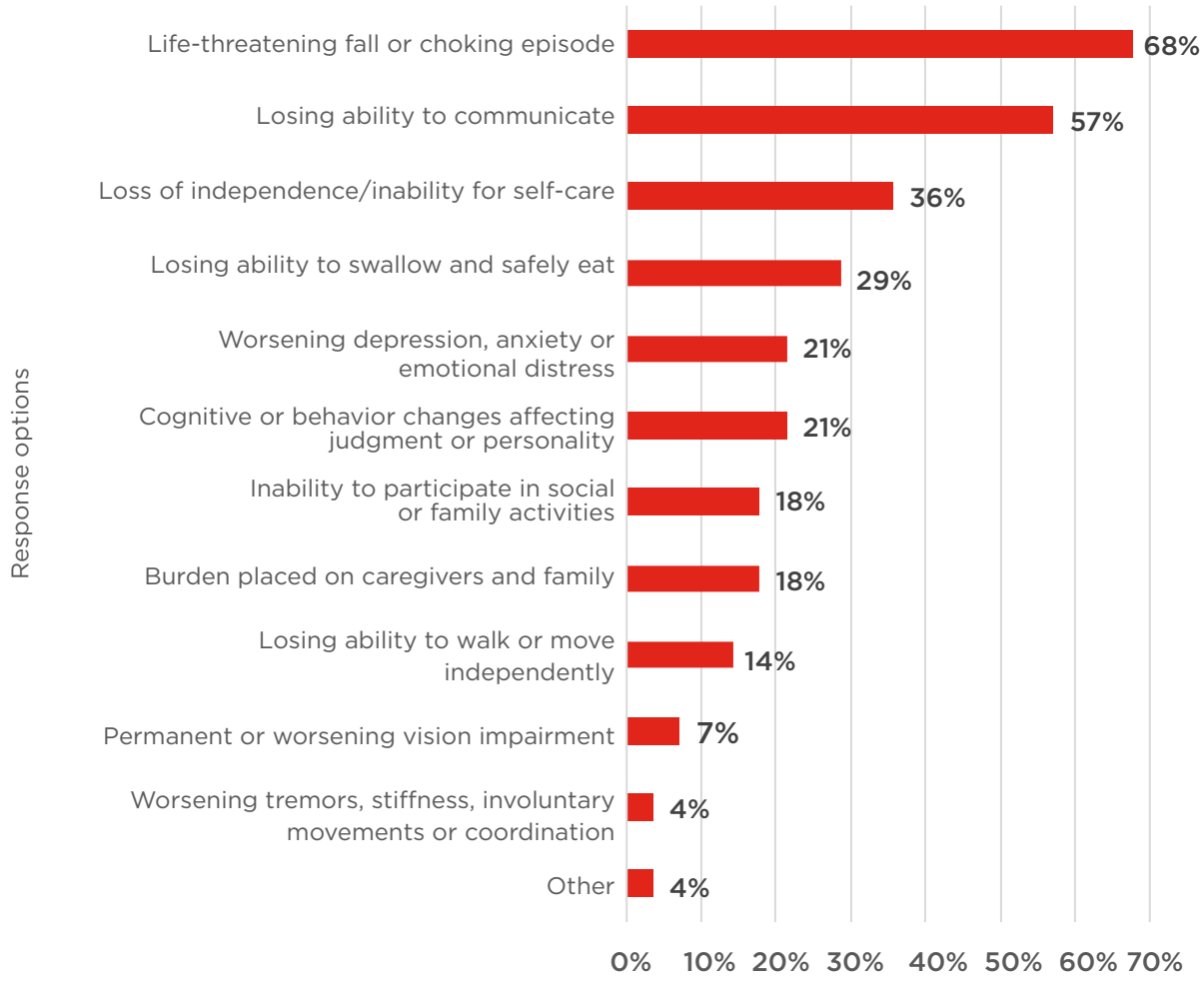

Q2. Select the most troublesome PSP-related health concerns that you or your loved one have had. Select TOP 3.
Response options
Balance or mobility problems (falls)
81%
Choking or difficulty swallowing
42%
Speech difficulties
36%
Visual impairment
31%
Urinary dysfunction and incontinence
28%
Cognitive or behavioral changes
22%
Loss of fine motor control
14%
Muscle stiffness or involuntary movements
14%
Sleep disturbances (insomnia or daytime sleepiness)
14%
Reduced emotional expressivity (facial masking)
8%
Excessive salivation or drooling
3%
Other
0%
0% 10% 20% 30% 40% 50% 60% 70% 80% 90%
Percentage of poll respondents who selected each option (n=36)

Q3. What specific activities of daily life are most important that you or your loved one are NOT able to do, or struggle with, due to PSP? Select TOP 3.



Percentage of poll respondents who selected each option (n=33)

Q4. What worries you most about your or your loved one's condition in the future? Select TOP 3.

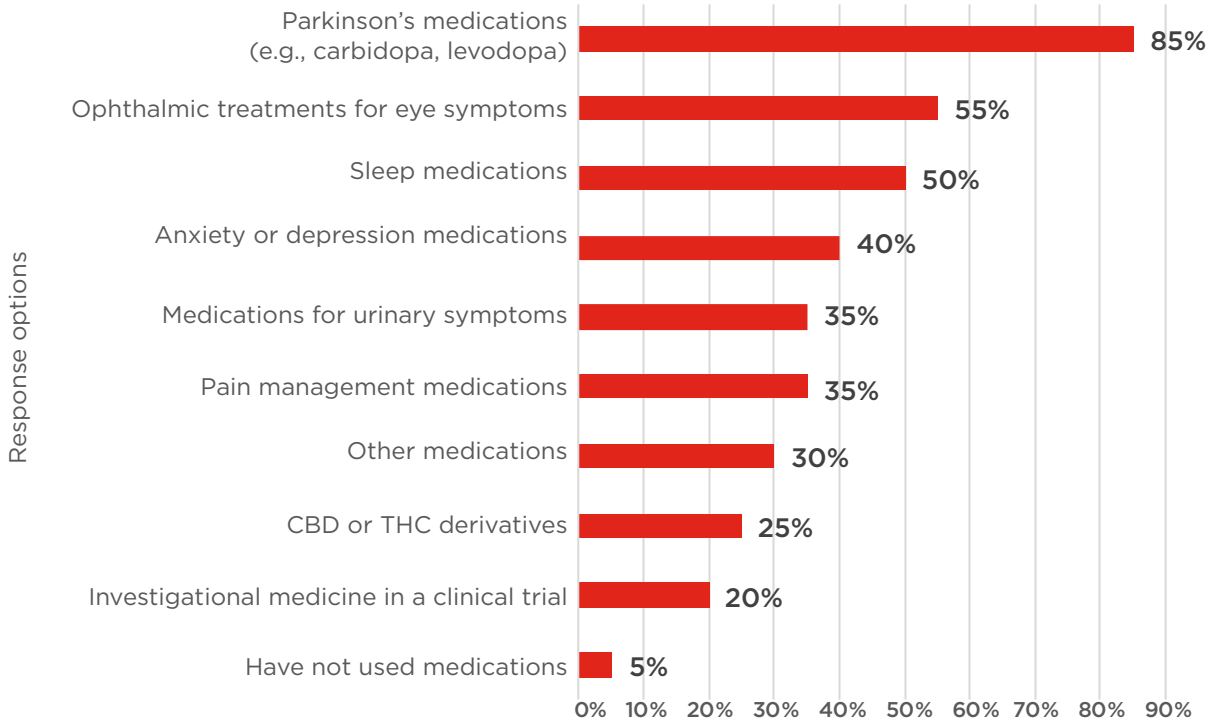


Percentage of poll respondents who selected each option (n=28)

Poll Responses to Topic 2: **Perspective on Current and Future Approaches to Treatment**

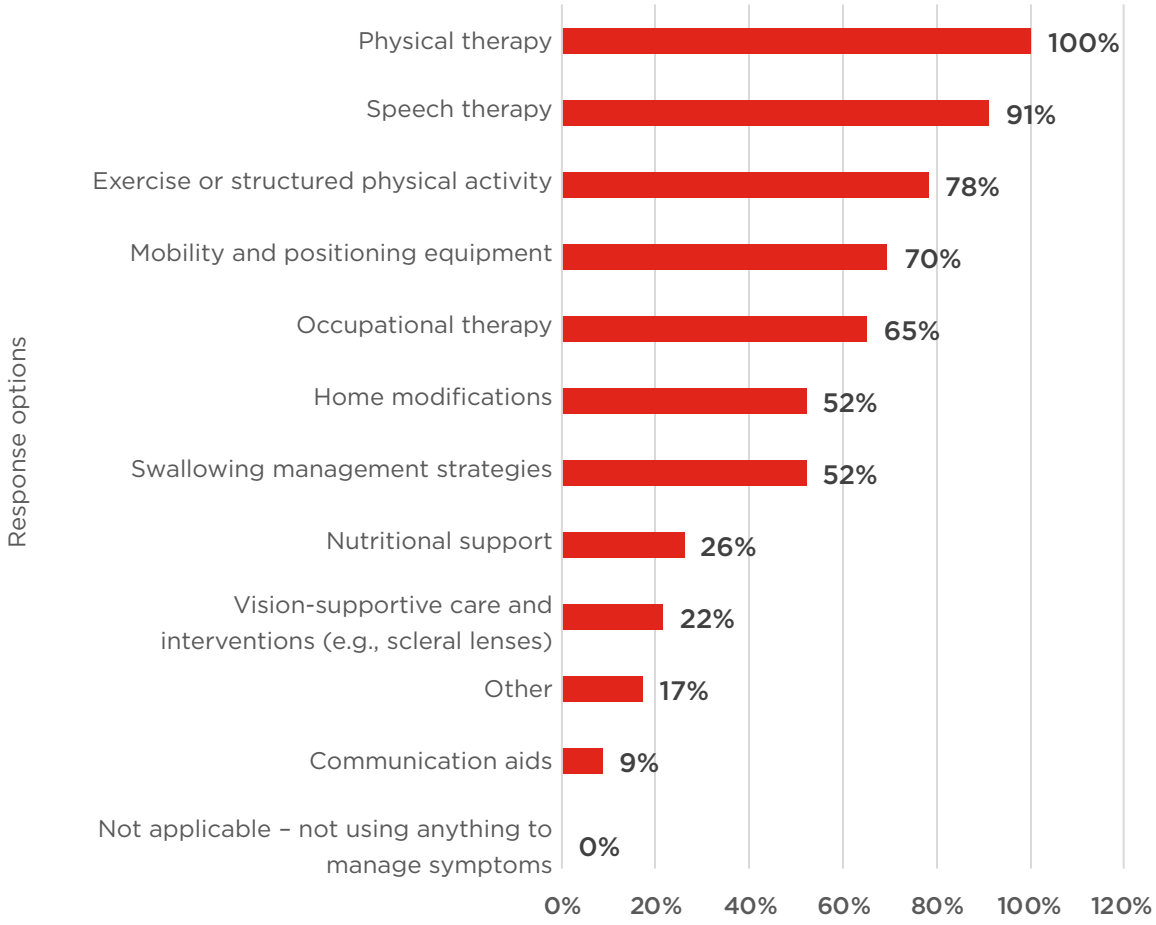
These graphs include the responses from those living with PSP, caregivers and family members who chose to participate in online polling at the EL-PFDD meeting. Bereaved caregivers and family members were invited to participate, answering on behalf of their loved one who had passed away. The number of individuals who responded to each polling question is shown below the X axis (n =x). For polls where the respondents could select more than one response, the sum of the responses is greater than 100%. While the response rate for these polling questions is not considered scientific data, it provides a snapshot of those who participated in the EL-PFDD meeting on PSP.

Q5. What medications have you or your loved one used to treat symptoms associated with PSP? Select ALL that apply.



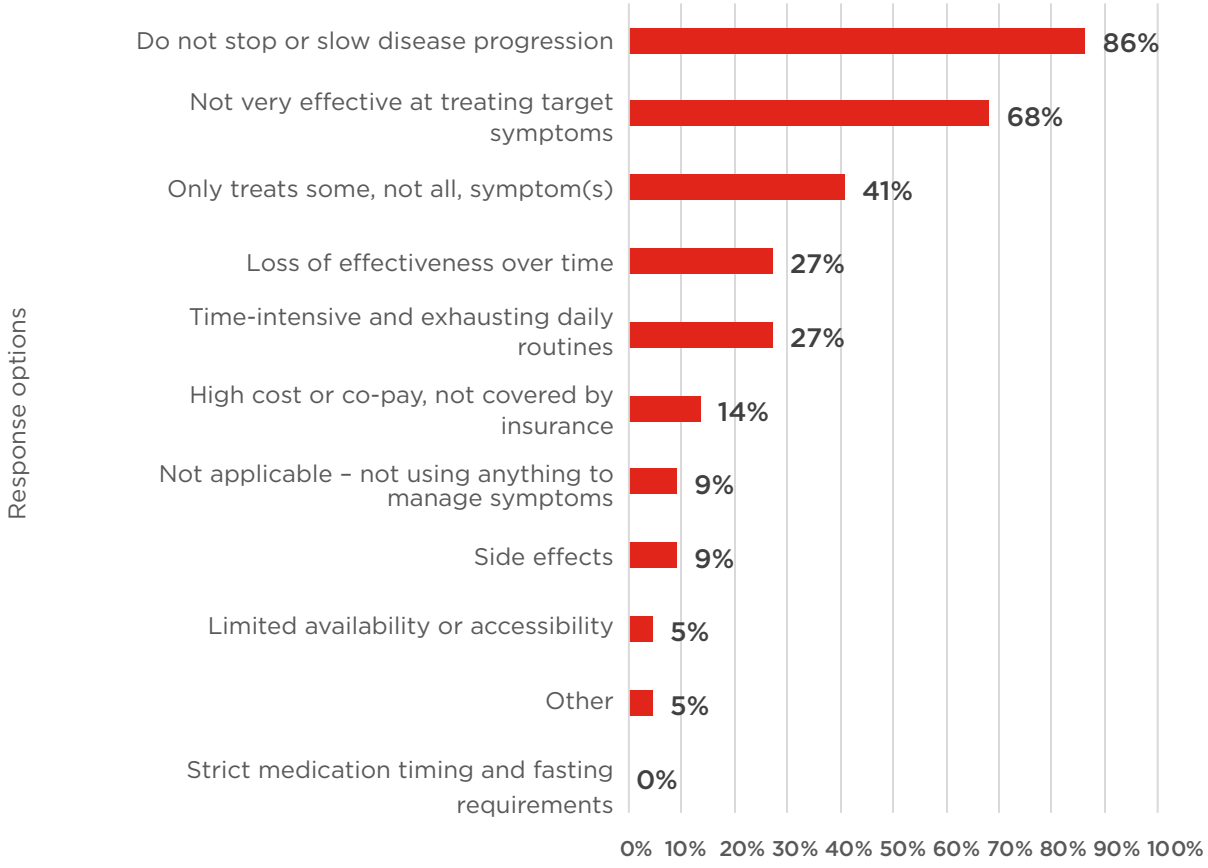
Percentage of poll respondents who selected each option (n=20)
Each respondent selected an average of 3.8 response options

Q6. Besides medications, what other treatment approaches have you or your loved one used to help manage the symptoms of PSP? Select ALL that apply.



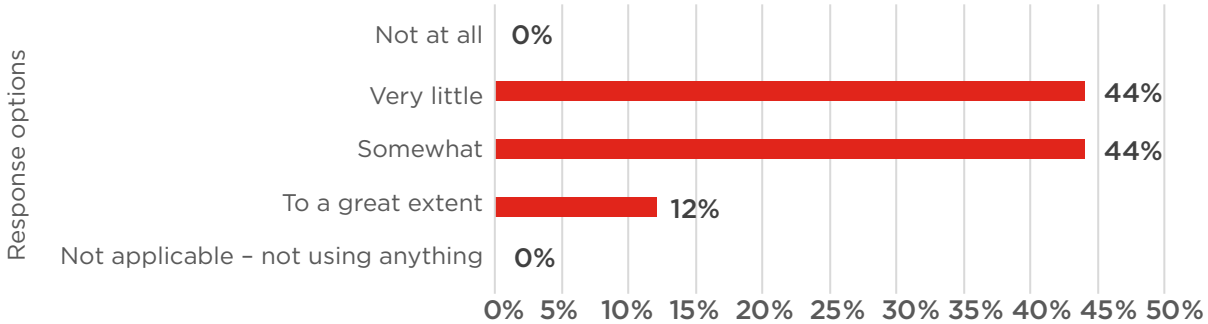
Percentage of poll respondents who selected each option (n=23)
Each respondent selected an average of 5.8 response options

Q7. What are the biggest drawbacks of your or your loved one's current treatment approaches? Select up to 3.



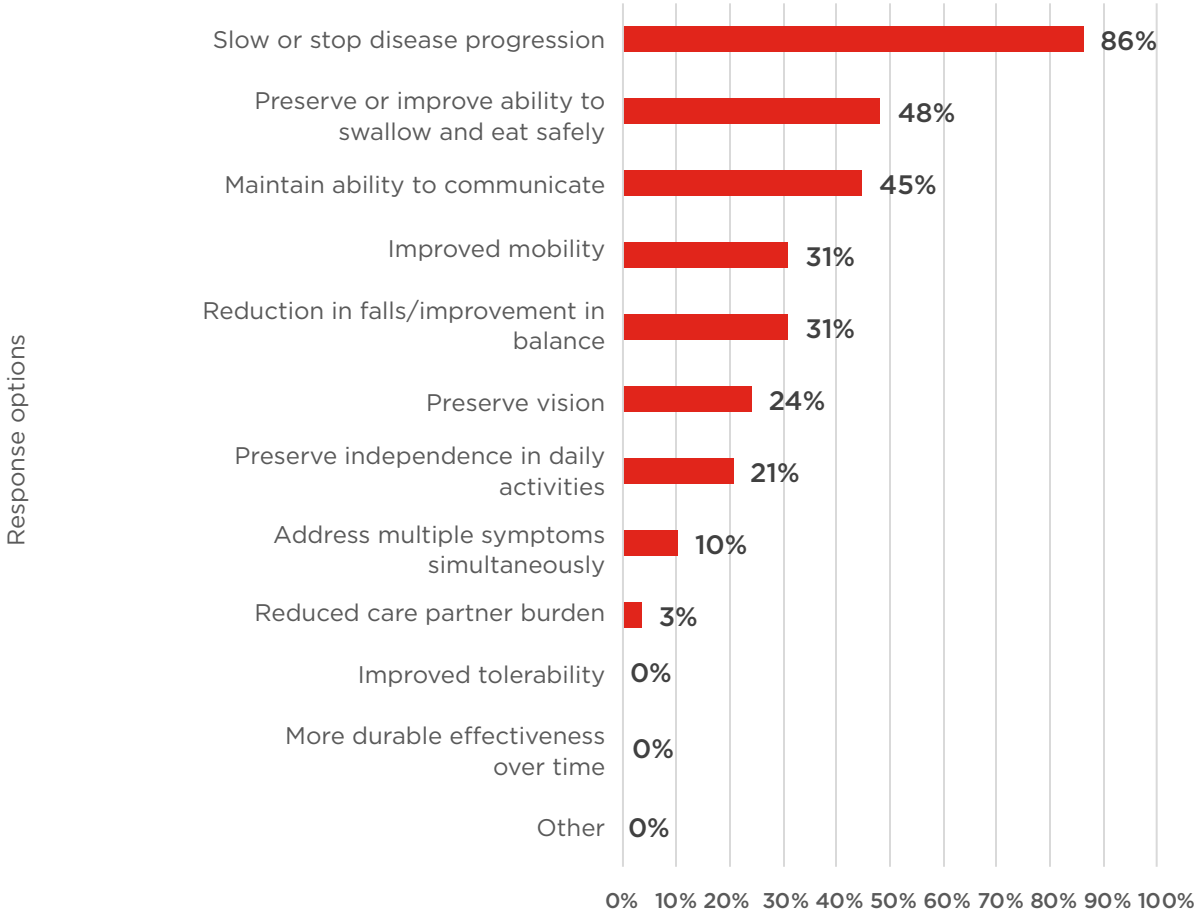
Percentage of poll respondents who selected each option (n=22)

Q8. How well does your current treatment regimen control your or your loved one's symptoms overall?



Percentage of poll respondents who selected each option (n=25)

Q9. Short of a complete cure, what specific things would you look for in an ideal treatment for PSP? Select TOP 3



Percentage of poll respondents who selected each option (n=29)

https://www.psp.org/pfdd