



PHYSIOTHERAPY MASTERCLASS

Jade Donnelly
24/09/2025

1

DISCLOSURES

- Member of the PSPA services committee

2

AIMS OF SESSION

- **Improve Clinical Understanding of Mobility Challenges in PSP & CBD** – Participants will develop a deeper understanding of the unique patterns of motor impairment, postural instability, gait disturbances, and fall risk associated with PSP & CBD
- **Practical Skills to Create Individualized Mobility Interventions** – Attendees will gain knowledge about best practice & strategies to optimize mobility and independence in people with PSP & CBD.
- **Recognition of Disease Progression and its Impact on Mobility** – Participants will learn to anticipate how mobility needs change over the course of PSP & CBD, from early balance and gait issues to late-stage immobility, enabling them to plan proactively and adjust interventions over time.

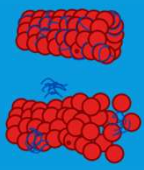
3

WHAT IS PROGRESSIVE SUPRANUCLEAR PALSY (PSP)?

- Previously known as Steele-Richardson-Olszewski syndrome
- Neurodegenerative tauopathy involving brain stem, basal ganglia, cerebral cortex and dentate nucleus of cerebellum
- **Progressive**- it steadily gets worse over time
- **Supranuclear**- it damages the nuclei that control the eye movements
- **Palsy**- it causes weakness
- Cause unknown
- 40-80y, mean age 63y (Litvan 1996)
- Ratio men: women 1.5:1
- Incidence 6 per 100,000 (Bower AL, Yu JT, Golbe LI, Litvan I, Lang AE, Höglinger GU. Advances in progressive supranuclear palsy and related neurodegenerative disorders: clinical, biomarkers, and therapeutic approaches. *Lancet Neurol*. 2017 Jul;16(7):552-563)
- Median survival 6 yrs (Litvan 1996)
- Mean interval from symptom onset to diagnosis is 3.6 to 4.9 years

4

TAUOPATHY



- Tau proteins stabilize microtubules and are normally found in low levels in a healthy brain.
- Microtubules are part of the cytoskeleton and are involved in maintaining cell structure.
- In tauopathy, tau builds up and forms tangles and clumps, causing microtubule disintegration.

5

Table 1. Progressive Supranuclear Palsy diagnostic criteria

	PSP - SS	PSP - PD	PSP - P	Others
Defined by pathology				
Definite	Vertical gaze palsy or vertical saccade slowing	Progressive gait	Progressive gait	Progressive gait
Possible	Slow vertical saccades	Progressive gait	Progressive gait	Progressive gait
Suggestive	Slow vertical saccades	Progressive gait	Progressive gait	Progressive gait

6

RED FLAGS FOR A DIAGNOSIS OF PSP	
1 Falls	Often backwards and without warning
2 Postural instability	Axial rigidity
3 Slowness of movement	Bradykinesia
4 Motor recklessness	Impulsivity
5 Eye problems	Restricted eye movement. May describe finding it difficult to walk downstairs due to problems with down gaze, reduced blink, double vision
6 Speech	Slurring of speech, soft voice
7 Swallowing difficulties	Liquids and solids, excessive saliva
8 Cognitive changes	Change in personality, irritability, apathy
9 Emotional lability	More easily brought to tears or laughter
10 No presenting tremor	


7

PSP : MEDIAN TIME TO SYMPTOMS

Walking aid required 3.1 years
Dysphagia 4.4 years
Wheelchair /bed bound 8.2 years

Median survival 5.5 to 10 years

Gotthe LI, Davis PH, Schoenberg BS, Duvelius RZ. Prevalence and natural history of progressive supranuclear palsy. *Neurology* 1988;38:1031-4



8

EVIDENCE

- There is limited evidence to suggest physiotherapy is helpful in PSP & CBS (Slade et al., 2019)
- "Although exercises may have the potential to benefit people living with PSP, currently there are few studies that adequately report all key elements of exercise therapy design, implementation and assessment." (Slade et al., 2019)

Exercise and physical activity for people with Progressive Supranuclear Palsy: a systematic review
Seun C Slade¹, David I Fluckstein², Jennifer L McGinley³, and Meg E Morris^{4,5}

However, there are numerous papers supporting physiotherapy for PD and the aging population. (Radder et al., 2020, also European PD Guidelines)

Benefits of remaining active both physically and mentally.

9

frontiers in Aging Neuroscience

Front Aging Neurosci. 2023 Dec 8;15:1294293. doi: 10.3389/fnagi.2023.1294293

Physiotherapy case reports on three people with progressive supranuclear palsy
Marilena Mateus^{1,2}, Alexandre Castro-Caldas³

3 cases of patients with PSP
motor and non-motor symptoms outlined
clinical progression described
physiotherapy intervention detailed
Reduced number of falls was achieved
improvements in gait and balance.

Exercise and physiotherapy appear to be beneficial for patients with PSP by enhancing their functionality and quality of life.

10

Physiother Theory Pract. Author manuscript; available in PMC 2024 May 1.
Published in final edited form as: Physiother Theory Pract. 2022 Jan 29;38(5):1071–1082. doi: 10.1080/09593985.2022.2032509

Training high level balance and stepping responses in atypical Progressive Supranuclear Palsy: A case report
Barlaine Croarkin¹, Krystle Robinson¹, Christopher J Stanley¹, Cris Zampieri¹

A multifactorial rehabilitation program can improve balance, eye-body coordination and strength in a high functioning patient with atypical PSP.

Intervention

- boxing
- stepping tasks
- treadmill training
- each with eye movement challenges
- total 15 hours of physical therapy
- 1 hour, 2 times a week.

Results

- improvements in eye-body coordination
- And limits of stability
- foot clearance
- task performance (squats, timed stepping).
- Follow-up demonstrated some decline from post-test results (reduced patient-reported adherence)

11

Patient and care partner views on exercise and structured physical activity for people with Progressive Supranuclear Palsy
Susan C. Slade¹, Christopher Bruce², Jennifer L. McGinley³, Bastiaan R. Bloem⁴, Meg E. Morris⁵

Published: June 5, 2020 • <https://doi.org/10.1371/journal.pone.0234265>

- People with PSP are keen to participate in exercise, especially early in the condition.
- People with PSP were rarely ref for therapy and had to seek it independently.
- People with PSP were uncertain about what activity and exercise would be helpful and at what dose.
- Carer burden, challenge of navigating the system.

12

Enablers to Exercise Participation in Progressive Supranuclear Palsy: Health Professional Perspectives

Meg E. Morris^{1,2*} Susan C. Stadel^{1,2} Christopher Bruce³
Jennifer L. McGinley⁴ Bastiaan R. Bloem^{5,7}

- Nursing and AHP believed that exercise, physical activities, movement rehabilitation are important in enabling those with PSP to live well.
- Uncertainty over how to deliver this.
- Lack of evidence-based recourses was seen as a barrier by health professionals.
- The paper highlighted the need for clinical guidelines.

13

Neuro Ther (2023) 12:228–247
<https://doi.org/10.1007/s40120-022-00420-1>



ORIGINAL RESEARCH

The Lived Experiences of People with Progressive Supranuclear Palsy and Their Caregivers

Gesine Respondek¹ · Diane Breslow² · Carol Amirghasvand³ ·
Boyd Ghosh⁴ · Bruno Bergmans⁵ · Leigh van Wyk⁶ ·
Tim Irfan⁷ · Robert Dossin⁸ · Cecile Vanderavero⁹

The paper highlighted that physiotherapy had been beneficial to patients but also highlighted the need for better communication between HCP, and also their education needs in relation to managing these conditions.

14

MOBILITY CHALLENGES IN PSP

15



16



THINGS TO CONSIDER

- Movement and mobility- postural instability, motor recklessness.
- Behavioural changes- apathy, impulsivity, compulsive, bradyphrenia, emotional lability
- Bladder and bowel-constipation, frequency and urgency.
- Vision- blepharospasm, photophobia, reduced blinking, double, tunnel, blurred, slow eye movements and complete loss of movement.
- Fatigue and sleep
- Pain- cramps and spasms

17

18

WHAT IS CORTICOBASAL SYNDROME (CBS)?

Corticobasal degeneration (CBD) is a rare, progressive neurological disease.

The term Corticobasal Syndrome (CBS) is also used.

- 5 per 100,000 in the UK
- Slightly more women than men
- Age onset is 60-70, but people may be affected from their 40's to 90's.
- Life expectancy is variable. Typically, it is in a range between 5-10 years, but individual health factors mean it can be shorter or longer.
- No curative treatment
- Clinical diagnosis

The principal areas of the brain affected are:

- The basal ganglia
- The cerebral cortex
- The 'cortical' in corticobasal degeneration refers to changes in language (aphasia), speech, memory, cognition, vision, clumsiness (apraxia) and alien limb
- The 'basal' in corticobasal degeneration refers to changes in movement, which can be slow and stiff (parkinsonism) and jerky (myoclonus), with contractions/dystonia and a risk of falls

19

RED FLAGS FOR A DIAGNOSIS OF CBD

1	Highly asymmetric progressive presentation	One side affected much earlier and worse than the other
2	Apraxia	Clumsy, awkward hands
3	Dystonia	Odd posture of hand, foot, arm or leg
4	Myoclonus	Quick involuntary jerks
5	Alien limb	Reaching or grasping automatically
6	Speech	Slurring or distortion of speech, halting, stuttering
7	Cognitive and behavioural changes	Change in personality, irritability, apathy, low mood, difficulties with organisation and planning

20

Table 2. Corticobasal Degeneration diagnostic criteria

Probable CBD	Possible CBD	FBSS *	NAV of PPA *	PPSP *
Age ≥ 50, ≥2 relatives with CBD and asymmetric presentation of 2 of: a) Limb rigidity or akinesia b) Limb dystonia c) Limb myoclonus	Asymmetric presentation of 1 of: Behavioural or personality change Visuospatial deficits	2 of: Executive dysfunction Behavioural or personality change Visuospatial deficits	Effortful agrammatic speech with 1 of: Impaired sentence but preserved word comprehension Groping distorted speech production (apraxia of speech)	3 of: Axial or asymmetric limb rigidity or akinesia Postural instability or falls Urinary incontinence Behavioural changes Slow or palsy of vertical saccades
2 of: d) Orobulbar or limb apraxia e) Cortical sensory deficit f) Alien limb phenomena	1 of: a) Cortical sensory deficit b) Alien limb phenomena			

Presentation needs to be insidious with a minimum duration of one year.

* Permitted phenotypes for Probable CBD is Probable CBD or FBSS or NAV WITH one CBD feature (a-f).

* Permitted phenotypes for Possible CBD is Possible CBD, FBSS or NAV, or PPSP WITH one CBD feature (b-f). Exclusion criteria is evidence of other diseases eg MSA, Amyotrophic Lateral Sclerosis, Lewy Body Disease, structural lesion, genetic cause or alternative primary progressive aphasia.

FBSS = frontal behavioural-spatial syndrome; NAV of PPA = Non fluent or agrammatic variant of primary progressive aphasia; PPSP = PSP syndrome.

21

THINGS TO CONSIDER

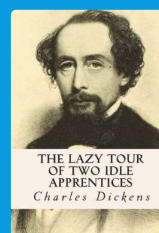
- Movement and mobility- asymmetrical, UL &/or LL becoming clumsy, awkward or stiff. Alien limb phenomenon. Apraxia and dystonia.
- Behavioural changes- apathy, anxiety, emotional lability
- Bladder and bowel-constipation, frequency and urgency.
- Vision-gaze palsy, visuospatial difficulty
- Fatigue
- Pain- cramps and spasms

22

PRACTICAL SKILLS

23

OBSERVATION SKILLS



THE LAZY TOUR
OF TWO IDLE
APPRENTICES
Charles Dickens

"A chilled, slow, earthy, fixed old man. A Cadaverous man of measured speech. An old man who seemed as unable to wink, as if his eyelids had been nailed to his forehead. An old man whose eyes- two spots of fire- had no more motion than (sic) if they had been connected with the back of his skull by screws driven through it, and rivetted and bolted outside, among his grey hairs."

"He had come in and shut the door, and he now sat down. He did not bend himself to sit, as other people do, but seemed to sink bolt upright, as if in water, until the chair stopped him."

The Lazy Tour of Two Idle Apprentices by Charles Dickens/Thomas Dobson Describes PPA in 1857
Movement Disorders, Vol 22, No 4, 2007

24

FALLS

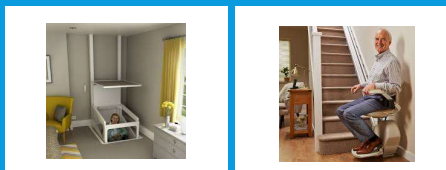
- Falls in PSP result from multiple factors including axial rigidity, bradykinesia, freezing of gait, reduced or absent postural reflexes, visual-vestibular deficits, impulsivity
- Brown et al 2020, highlighted that frequent fallers have been found to have disproportionately poor performance on turning and pivoting.
- In PD en bloc turning, in PSP pivot carelessly

Consider:-

- Backward chaining
- Turning in a wide arc



25



STAIRS, STAIR LIFTS OR SINGLE LEVEL LIVING

26

Stairs



> Phys Ther. 2008 Feb;88(2):240-50. doi: 10.2522/ptj.20070159. Epub 2007 Dec 11.

Gaze control and foot kinematics during stair climbing: characteristics leading to fall risk in progressive supranuclear palsy

Richard P Di Fabio¹, Cris Zampieri, Paul Tuite

Affiliations + expand

PMID: 18073265 DOI: 10.2522/ptj.20070159

Deficits in gaze control may influence stepping behaviours and increase the risk of trips or falls during stair climbing.

27

Vision: Vertical Gaze Palsy

These preliminary findings support the use of balance and eye movement exercises to improve gaze control in PSP.



Randomized Controlled Trial > Arch Phys Med Rehabil. 2009 Feb;90(2):263-70. doi: 10.1016/j.apmr.2008.07.024.

Improvement of gaze control after balance and eye movement training in patients with progressive supranuclear palsy: a quasi-randomized controlled trial

Cris Zampieri¹, Richard P Di Fabio

Affiliations + expand

PMID: 19236679 DOI: 10.1016/j.apmr.2008.07.024

28

- Gait, turning & mobility aids
- Sit to stand/ hip hinge, build up momentum
- Balance
- Step standing stance/ power stance
- Bed mobility
- Postural management *eating /drinking/retrocollis

TASK SPECIFIC EXERCISES



29

NEW EXERCISE CLASSES FOR PEOPLE WITH PSP & CBD

People living with PSP & CBD can now access specialist exercise classes delivered by Neuro Heroes. We spoke to Laura Douglas, Physiotherapist and co-founder of Neuro Heroes. Here Laura explains why exercise is so important for people with conditions like PSP & CBD.



LAURA DOUGLAS
"We always say exercise is medicine for people with neurological conditions."

"Joining PSP's Exercise Sessions has been good fun and has given me a new range of exercises to do. Previously I'd been part of a Parkinson's exercise class, but much of what they did was not appropriate for me. The Neuro Heroes exercises are much more tailored to my condition. The feedback was also helpful as the instructor could see what we were doing and help us individually with the things we were finding difficult."

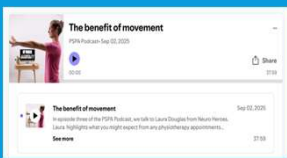
"Hugh, my husband made notes during the class and we now repeat what we do in class most days which has been helpful in improving the range of things I can do. We even took our tablet on holiday so we could join the class from Wales!"



BETH SHEPHERD-WALWYN, LIVING WITH CBD

Our Online exercise sessions are free for anyone who joins PSPA. If you are interested in joining an exercise class please visit www.pspassociation.org.uk/pspa-online-exercise-sessions

30



NEUROHEROES
PSP+CBD Boost

Week 3	Content	Time allocation
Wellness and Neurocoping	As per the top of this document	Under 5 mins
Hands and face To get things going	Shower and morning routine Wash hair, finger tips on scalp or away from head a little Move feet, make lots of bubbles! Look up and run hands through hair to rise Curl hair, both sides Put moisturiser on face, gently Big smile and set out breakfast bath + mouthwash itself	5 mins
Warm up in the chair Slow and steady One task at a time	Marching legs, clasp feet if able Alternate finger points up to the ceiling Head raises Backward arm circles to open chest Head dips and in front Explode feet forwards from shoulders to open hands, pull arms back Alternate knee extensions	5 mins

www.neuroheroes.co.uk
hello@neuroheroes.co.uk

Block of 8 once a week sessions

Fully funded by PSPA

From home on Zoom - No kit needed

Support with booking and set up

31



NEUROHEROES

I feel more capable using my arms and legs

I am able to participate more in everyday life and I have more energy

I get a great sense of achievement at the end of the class when I have managed to do some of the exercises

These PSP specific sessions feel so different to other sessions - I can't put my finger on exactly why that is but please keep them going

We would definitely recommend the program but for us it was too late in the progress of the illness. It would have been ideal eighteen months ago before she lost so much mobility and confidence

Loved the facial expressions and enthusiasm

I wish these sessions had been available when I was first diagnosed

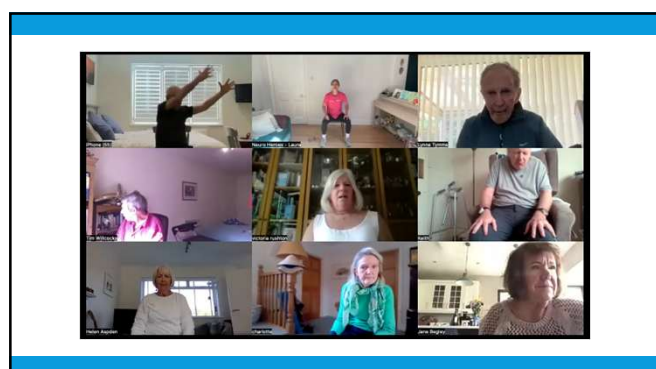
The classes have given me confidence in moving.

I haven't used this technology for anything like this before and I found it very stimulating and rewarding as the environment wasn't threatening or stressful

I feel really good at the end of the course and that I'm part of a community of people in the same situation.

These PSP specific sessions are invaluable. They go at the right pace and seem to include everything and leaves one feeling positive

32



33

DISEASE PROGRESSION

34

What happens if patients receive little or no therapy or experience periods of inactivity?

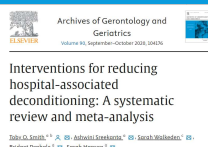
35

HAD (HOSPITAL ACQUIRED DECONDITIONING)

Many of these patients could prematurely end up in a care home because of 'deconditioning' and the loss of functional abilities in hospital. (*British Geriatric society*)

- There are many factors which can impact on HAD,

The meta-analysis by Smith et al, 2020, highlights the many challenges, and multi factorial problems HCP face when managing these patients in the acute setting.



36

ACCELERATED DECONDITIONING FROM PROLONGED BEDREST WITHOUT MOBILISATION IN ATYPICAL PARKINSONIAN SYNDROME PATIENTS: IMPORTANCE OF EARLY MOBILISATION IN DETERIORATING CONDITIONS

- For PSP, most notable was the change in mobility (mobile on admission/hoist on discharge)
- PSPRS, the score increased by 19 points in a 14-month period. (On average literature suggests a 1 point increase each month, we anticipate a 10-point change in a year).
- This is a small-scale study, but it highlights the vulnerability of these patients to deconditioning when in hospital.

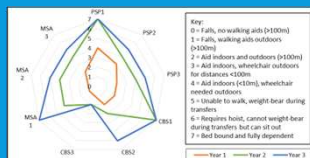
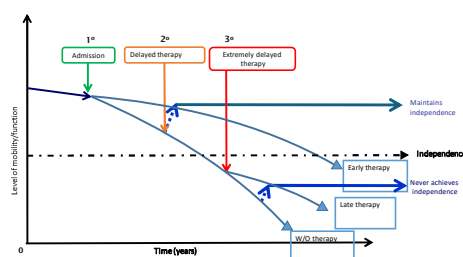


Figure 1| APS patients' walking profile assessments score the deterioration of ambulation ability over 3 years. The y-axis scale shows increasing numbers, reflecting the difficulty of mobilising independently.

37

Time is function

Figure 1 | Timing of intervention on admission



38

BEDS

Low beds +/- additional floor mattress

Sensor mats



39

Dystonia

Mechanism: A condition involving involuntary, sustained muscle contractions that cause abnormal, often repetitive, movements and postures.

Brain Involvement: Typically involves dysfunction in the basal ganglia, a part of the brain that helps regulate muscle signals.

Presentation: Involves continuous, awkward postures or movements that can fluctuate, improve with certain tasks, or be present even at rest.

Spasticity

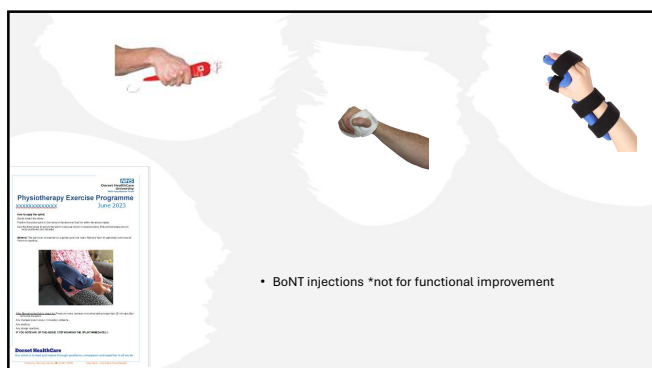
An overactive stretch reflex that causes muscles to stiffen and resist sudden, passive movement.

Often arises from damage to the cerebral cortex or spinal cord pathways that control muscle movement.

Characterized by muscle stiffness and spasms that worsen with increased speed of passive movement.

Charlotte Campbell MS Neurology OT
Dean Swanton Neurology Specialist Practitioner

40

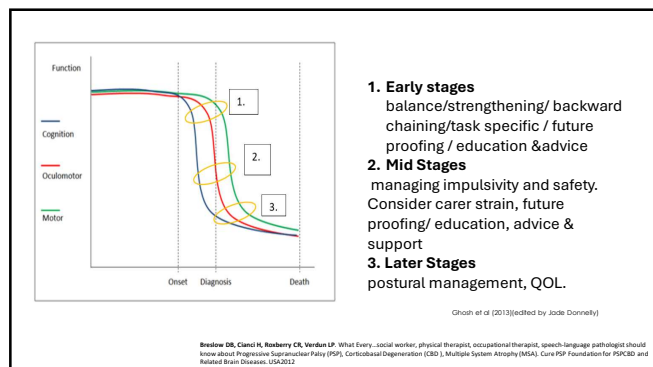


- BoNT injections *not for functional improvement

41




42



43

BLUE BADGE APPLICATION



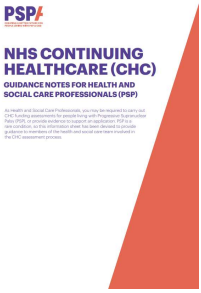
Consider :

- Gait and risk of falls, level of independence
- Vision
- Impulsivity

44

NHS CONTINUING HEALTHCARE (CHC)

- Keep a diary – family members underestimate the complexity of care they provide
- Highlight the hidden symptoms and complexities e.g. risk taking
- Evidence is key- be descriptive and explicit
- Well managed needs are still needs



45

IN SUMMARY

- There is no cure for these conditions, but there is plenty which we can do or offer to try and improve the quality of life for those under our care.
- Physiotherapy has an important role to play in the management of these conditions.
- Early intervention
- Proactive management
- More research is needed

46



THANK YOU FOR LISTENING –

apscoordinator@uhs.nhs.uk
Jade.donnelly@uhs.nhs.uk

Mobile 07824124626



47