

PHYSIOTHERAPY MASTERCLASS

University Hospital Southampton  NHS Foundation Trust

Jade Donnelly
24/09/2025



Wessex
Neurological
Centre

PSPA
CREATING A BETTER FUTURE FOR
PEOPLE LIVING WITH PSP & CBD

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A solid blue vertical bar on the left side of the slide, spanning from the top to the bottom.

DISCLOSURES

- Member of the PSPA services committee

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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.

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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 (Borod AL, Yu JT, Gobeil J, Iversen L, Lang AE, MacLellan GL. Advances in the understanding of progressive supranuclear palsy: new diagnostic criteria, biomarkers, and therapeutic approaches. Lancet Neurol. 2017 Jul;16(7):553-563)
- Median survival 6 yrs (Litvan 1996)
- Mean interval from symptom onset to diagnosis is 3.6 to 4.9 years

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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.

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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 salvia
8 Cognitive changes	Change in personality, irritability, apathy
9 Emotional lability	More easily brought to tears or laughter
10 No presenting tremor	

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PSP : MEDIAN TIME TO SYMPTOMS

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

Goette LI, Davis PH, Schoenberg BS, Duvoisin RC. Prevalence and natural history of progressive Supranuclear palsy. *Neurology* 1988;38:1031-4

Median survival 5.5 to 10 years





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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."¹¹ (Slade et al, 2019)

Exercise and physical activity for people with Progressive Supranuclear Palsy: a systematic review

Susan C Slade ¹, David I Finkelstein ², Jennifer L McGinley ³, and Meg E Morris ⁴

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

• Benefits of remaining active both physically and mentally.

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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

Mariana Mateus ¹, Alexandre Carvalho ²

• Author information • Article notes • Copyright and License information

PMCID: PMC10739486 PMID: 35145007

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

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• 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

Farilaine Croarkin ¹, Krystle Robinson ¹, Christopher J Stanley ¹, Cris Zampieri ¹

• Author information • Article notes • Copyright and License information

PMCID: PMC9334456 NIHMSID: NIHMS1776464 PMID: 35098865

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

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Patient and care partner views on exercise and structured physical activity for people with Progressive Supranuclear Palsy

Susan C. Slade ¹, Christopher Bruce, Jennifer L. McGinley, Bastiaan R. Bloem, Meg E. Morris

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.

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

Meg E. Morris^{1,2*}, Susan C. Slade^{1,2}, Christopher Bruce³, Jennifer L. McGinley⁴, Bastiaan R. Bloem^{5,6,7}

- 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 resources was seen as a barrier by health professionals.
- The paper highlighted the need for clinical guidelines.

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Neuro Ther (2023) 12:239–247
<https://doi.org/10.1007/s40120-022-00420-1>

ORIGINAL RESEARCH

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

Gesine Respondek  · Diane Breslow · Carol Amighiaavand · Boyd Ghosh  · Bruno Bergmann  · Leigh van Wyk · Tim Irfan · Robert Dossin · Cecile Vandervrevo

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.

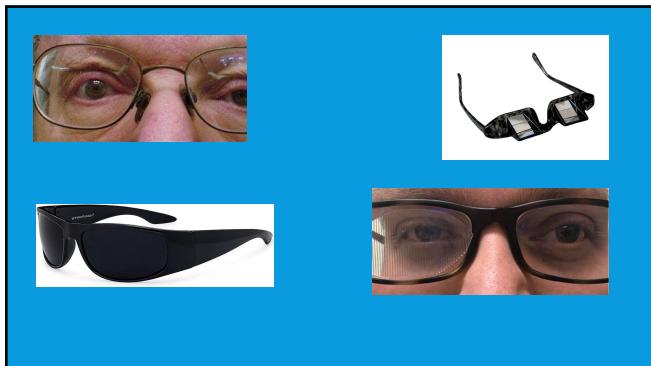
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MOBILITY CHALLENGES IN PSP

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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

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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 50-70, 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

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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

Table 2. Corticobasal Degeneration diagnostic criteria

Probable CBD	Possible CBD	FBSS *	NAV of PPA *	PSPS *
Age ≥ 50, with relative CBD and asymmetric presentation of 2 or:	Asymmetric presentation of 1 or:	2 of: Executive dysfunction, language or personality change, Visuospatial deficits	3 of: Axial or symmetric apraxia, agrammatic or nonfluent speech, preserved word comprehension (good, distorted speech production (slow or pausy speech), slow or pausy or of vertical saccades	
a) Limb rigidity or akinesia				
b) Limb dystonia				
c) Limb myoclonus				
2 or:	1 of:			
d) Orobuluccal or limb apraxia				
e) Cortical sensory deficit				
f) 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 PSPS 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; PSPS = PSP syndrome.

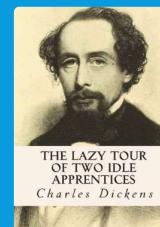
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THINGS TO CONSIDER

- 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

PRACTICAL SKILLS

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 who seemed as unable to move his head, as if his motion that (sic) if they had been connected with the back of his skull by screws driven through it, and riveted 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 Laz Tour (online, accepted by Charles Dickens/Charles Dickens Decades PSP in 08/17)
Movement Disorders, Vol 22, No 4, 2007

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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



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STAIRS, STAIR LIFTS OR SINGLE LEVEL LIVING

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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 Fabio ¹, 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.

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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 Zampieri ¹, Richard P Di Fabio
 Affiliations + expand
 PMID: 19236979 DOI: 10.1016/j.apmr.2008.07.024

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- 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**



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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 important for people with neurological conditions."



BETH SHEPHEARD-WALWYN, LIVING WITH CBD
"Joining PSPA'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 wasn't 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."

NEURO HEROES

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

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The benefit of movement
PSP+CBD Boost

NEURO HEROES
PSP+CBD Boost

Week 3	Content	Time allocation
Weeks and Monthkeeping	As per the top of this document	Under 5 mins
Hands and Face	To get things going	5 mins
Warm up in the chair	Wash hair, finger tips on scalp or away from head a little Wash face, finger tips on face Look up and run hands through hair to rinse Gently stretch arms and legs Put moisturiser on face, gently Big smile and act out brushing teeth + mouthwash swell	5 mins
One task at a time	Marching legs, stamp feet if able Alternating finger points up Marching arms, stamp hands if able Alternating arm points up Chair dips, open hands, pull arms back Alternating 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

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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 progression of illness. It should 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 feel really good at the end of the course and that I'm part of a community of people in the same situation.
I haven't used this technology for anything like this before and I found it so rewarding and rewarding as the environment wasn't threatening or stressful
These PSP specific sessions are invaluable. They go at the right pace and seem to include everything and leaves one feeling positive

NEURO HEROES

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DISEASE PROGRESSION

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

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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.

 Archives of Gerontology and Geriatrics
Volume 64, September–October 2020, 304–316

Interventions for reducing hospital-associated deconditioning: A systematic review and meta-analysis
Tobias Stoeckli,^{1,2} A. S. Adwani,³ S. Willemsen,⁴ B. Prakash,⁵ S. Hennemuth,⁶ B. Prakash,⁷ S. Hennemuth,⁸ S. Hennemuth,⁹ S. Hennemuth,¹⁰ S. Hennemuth,¹¹ S. Hennemuth,¹² S. Hennemuth,¹³ S. Hennemuth,¹⁴ S. Hennemuth,¹⁵ S. Hennemuth,¹⁶ S. Hennemuth,¹⁷ S. Hennemuth,¹⁸ S. Hennemuth,¹⁹ S. Hennemuth,²⁰ S. Hennemuth,²¹ S. Hennemuth,²² S. Hennemuth,²³ S. Hennemuth,²⁴ S. Hennemuth,²⁵ S. Hennemuth,²⁶ S. Hennemuth,²⁷ S. Hennemuth,²⁸ S. Hennemuth,²⁹ S. Hennemuth,³⁰ S. Hennemuth,³¹ S. Hennemuth,³² S. Hennemuth,³³ S. Hennemuth,³⁴ S. Hennemuth,³⁵ S. Hennemuth,³⁶ S. Hennemuth,³⁷ S. Hennemuth,³⁸ S. Hennemuth,³⁹ S. Hennemuth,⁴⁰ S. Hennemuth,⁴¹ S. Hennemuth,⁴² S. Hennemuth,⁴³ S. Hennemuth,⁴⁴ S. Hennemuth,⁴⁵ S. Hennemuth,⁴⁶ S. Hennemuth,⁴⁷ S. Hennemuth,⁴⁸ S. Hennemuth,⁴⁹ S. Hennemuth,⁵⁰ S. Hennemuth,⁵¹ S. Hennemuth,⁵² S. Hennemuth,⁵³ S. Hennemuth,⁵⁴ S. Hennemuth,⁵⁵ S. Hennemuth,⁵⁶ S. Hennemuth,⁵⁷ S. Hennemuth,⁵⁸ S. Hennemuth,⁵⁹ S. Hennemuth,⁶⁰ S. Hennemuth,⁶¹ S. Hennemuth,⁶² S. Hennemuth,⁶³ S. 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ACCELERATED DECONDITIONING FROM PROLONGED BEDREST WITHOUT MOBILISATION IN ATYPICAL PARKINSONIAN SYNDROME PATIENTS: IMPORTANCE OF EARLY MOBILISATION IN DETERIORATING CONDITIONS

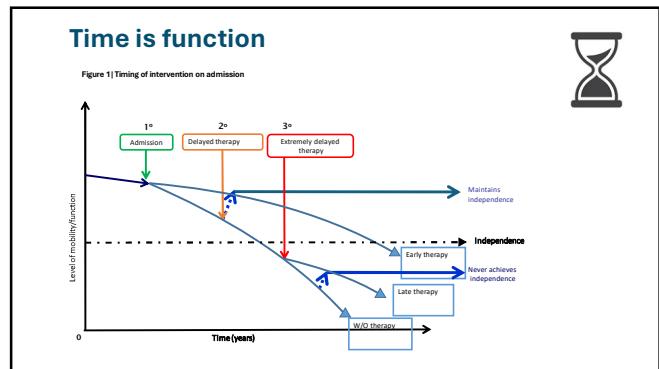
For PSP, most notable was the change in mobility (mobile on admission/hoist on discharge)

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 patient's 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



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-Hill Neurology OT
Dawn Suttor Neurology Specialist Practitioner OT

40

• BoNT injections *not for functional improvement

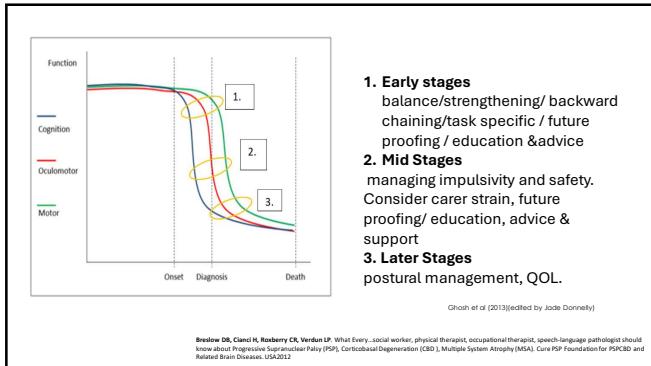
Physiotherapy Exercise Programme
June 2023

Donset HealthCare
www.donsethealthcare.com

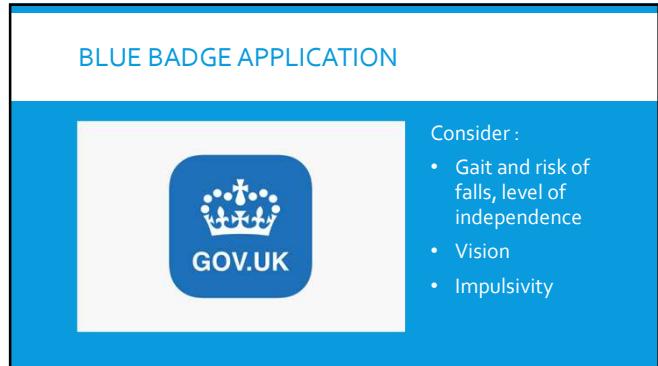
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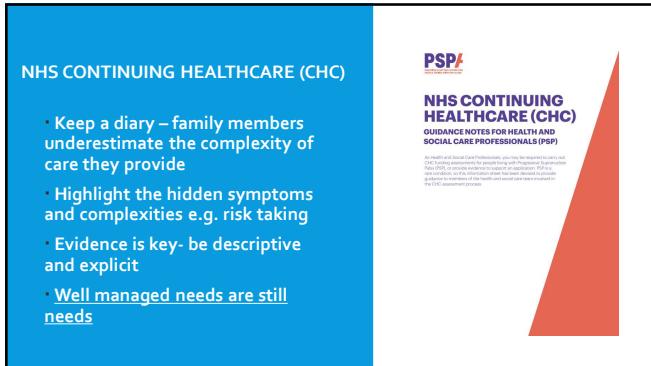
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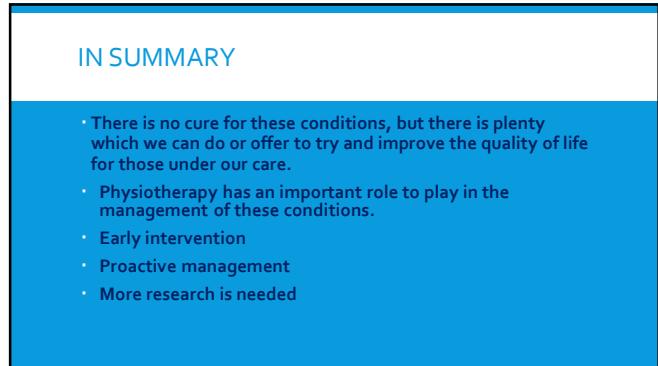
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