

PSPA + Neuro Heroes Update

January 2025



Headlines

- 16 months of weekly classes
- 104 assessments completed
- 74 people have attended an eight week block of sessions
- Many have attended more than one course and are keen to continue accessing classes
- Currently oversubscribed with 33 active weekly attendees

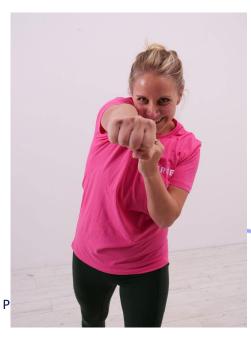


Courses attended

74 people with CBD or PSP have come to a block of eight Neuro Heroes sessions

13 of these people have CBD 61 of these people have PSP

- 31 people have signed up/completed 1 course
- 10 people have signed up/completed 2 courses
- 6 people have signed up/completed 3 courses
- 6 people have signed up/completed 4 courses
- 9 people have signed up/completed 5 courses
- 8 people have signed up/completed 6 courses
- 4 people have signed up/completed 7 courses
- 4 people currently attending other higher level Neuro Heroes classes to meet their needs, funded by P





Warwick Edinburgh Mental Wellbeing Scale

We ask all participants to complete the 14-item WEMWBS scale before and after completing a block of eight sessions

This asks questions about wellbeing on a 5 point scale such as

'I've been feeling interested in other people' - none of the time / rarely / sometimes / often / all of the time

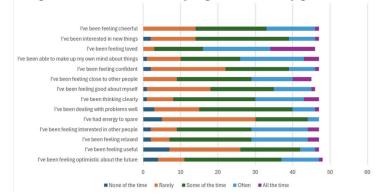
'I've been feeling good about myself' - none of the time / rarely / sometimes / often / all of the time

45 people responded to the questionnaire both before and after their block of eight sessions

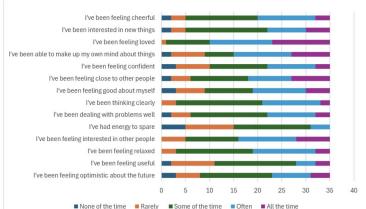
- The average score was 42.5 before classes and 45.5 following classes
- The scale categorises clients as low wellbeing where total score is less than 43, moderate for 43-60 and high for greater than 60
- Therefore overall the attendees have moved from low wellbeing to the moderate wellbeing category
- The most significant changes were seen in these categories, however they were very small:
 - 'I've been dealing with problems well'
 - 'I've been thinking clearly'
 - 'I've been feeling close to other people'
- These are smaller differences than when the data was analysed four months ago, which might reflect the fact that clients are repeating the course and their condition is progressing over time as they work with Neuro Heroes



Survey results before physiotherapy classes



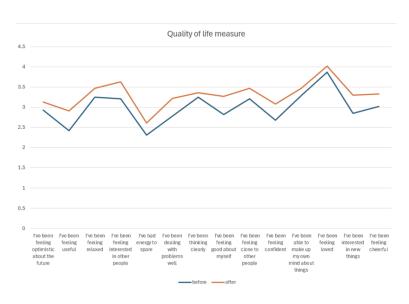
Survey results after physiotherapy classes





QUALITY OF LIFE

This graph presents data collected from patients before and after their 8 sessions with Neuro Heroes, measuring their quality of life, overall well-being, and holistic progress.





Client Feedback

- 46 people have completed the feedback form
- 23 people think 8 sessions is about right, with 11 wanting more
- On the form all respondents would recommend Neuro Heroes and only one person said they don't want to continue as their condition is too far progressed
- Some themes emerged from the feedback form:
 - People reported feeling more confident and capable moving around
 - People enjoyed the sessions and looked forward to them
 - People liked having a weekly routine of attending
 - Classes were appropriate for people with PSP and CBD

"Neuro Heroes seem to be able to **encourage** one to **keep on trying** with exercises even when one hasn't been able go do very much of a class, they are still **full of encouragement** and **enthusiasm**. I hope this class will continue and become a permanent fixture at Neuro Heroes."



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

I have really enjoyed the exercises and looked forward to Tuesday mornings very much I wish these sessions had been available when I was first diagnosed expressions and enthusiasm

Loved the facial

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 very stimulating 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**



Reflections from Neuro Heroes

- It sometimes takes people a while to sign up for courses but they tend to want to stick with us!
- We consistently see fewer people with CBD
- Have two levels of ability works well in classes. Combining CBD and PSP classes appears to be working well and allows us to support 30 people a week with either condition
- People are keen to work on balance but our priority is client safety, so the level of challenge has been reduced since seeing some falls in PSP and CBD classes
- Care partners are vital to the success of the class and engagement
- Clients like the variety of sessions and the dynamic workouts
- Informal feedback tells us many who don't continue feel they can't because their condition is too far progressed, and many comment they would have liked to access these sessions earlier in their PSP or CBD journey therefore the challenge is to engage those who are closer to diagnosis
- Some people find the 14-item Wellbeing questionnaire tiring to complete and many don't complete it. We could consider using the shortened 7-item version
- We have created a Zoom instruction sheet to support those who need it but generally technology isn't a barrier to those who have signed up



What does the class actually involve?

The PSP/CBD specific classes are at two different levels.

- Both are done sitting in a chair.
- No equipment is needed.
- Both classes include a warm up for the hands, face, arms, legs. There is a functional focus, for example exercises to work on reaching. Strength and fitness section and a stretching section.
- Rests are taken between each section and people are very much encouraged to work at their own pace and join in where they can.
- In the higher level class there is some practice at sit to stand and standing balance, the lower level class does sit to stands only, using their normal equipment or assistance (standing is not compulsory for the class and lots of people do bottom lifts instead of standing).
- For safety reasons during the sit to stand and standing sections, if required walking aids are used and a care provider (carer/family member) can assist.



How to access the classes?

- Complete an online assessment form on our website <u>www.neuroheroes.co.uk</u> or on a direct link from the PSPA website <u>https://www.pspassociation.org.uk/pspa-online-exercise-sessions/</u>
- Become a member of the PSPA
- Neuro heroes will look at your assessment forms, a physio will recommend the appropriate level class and organise booking the classes for you.
- The classes are fully funded by the PSPA.
- Come and give us a try, keep moving and have some fun!







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