

# STATE OF DIAGNOSIS FOR PROGRESSIVE SUPRANUCLEAR PALSY (PSP) AND CORTICOBASAL DEGENERATION (CBD) 2023



**PSP & CBD are two rare degenerative neurological conditions caused by the premature loss of nerve cells in the brain, resulting from a build-up of Tau proteins.**

**Symptoms include problems with balance, speech, swallowing, sight, and cognition. Both conditions are terminal with a life expectancy of on average seven years. There are currently no treatments or cure.**

There are over 4,000 people living with a PSP or CBD diagnosis in the UK, with an estimated 10,000 people thought to have either condition.

In 2022, PSPA conducted a survey of people living with PSP & CBD to examine if diagnosis had improved since data was last collected in 2016. On both surveys we had a robust response of more than 400 people taking part.

Unfortunately, we have not seen any significant change in how quickly people are being diagnosed with PSP or CBD. Challenges remain with getting a referral from a GP to a neurologist, the speed at which people are seen by neurologists and then getting a correct diagnosis.

While most people felt at least reasonably supported and informed when they receive their diagnosis, there is still room for improvement. More positively, COVID and resource pressures in the NHS does not seem to have negatively affect how people experience the diagnosis process (once it finally happens).

Disappointingly, fewer people in 2022 said they had heard of PSP & CBD at the point they had been diagnosed, suggesting wider awareness of the diseases have not improved.

**THERE ARE AN ESTIMATED  
 10,000 PEOPLE THOUGHT  
 TO HAVE PSP OR CBD  
 IN THE UK.**

## THE CHALLENGES

### LACK OF AWARENESS AMONGST HEALTH AND SOCIAL CARE PROFESSIONALS

The lack of awareness of PSP & CBD symptoms creates a barrier to getting a referral from a GP to a neurologist. For nearly half of people this takes over six months although it seems it might be taking fewer visits than in 2016. Half of the people are referred to other health professionals first, most often physiotherapists, memory clinics and geriatricians. 11% were referred to three or more other health professionals before getting a referral to a neurologist.

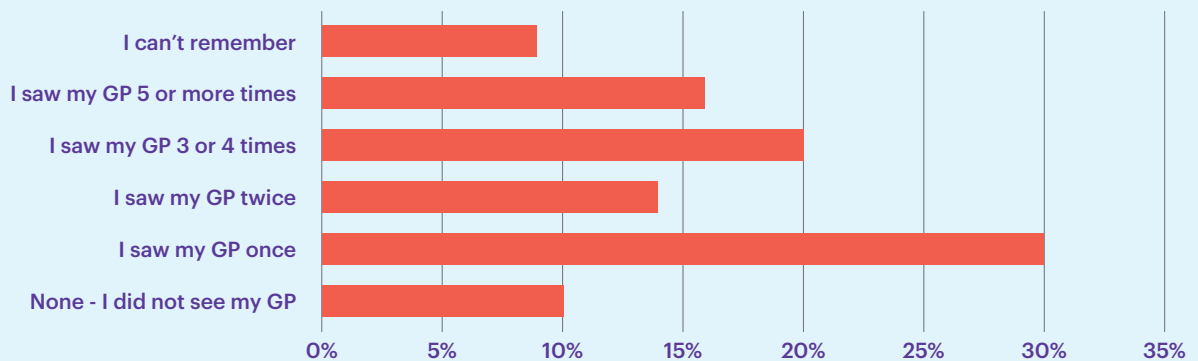
When asked how many times respondents had seen a GP (family doctor) about the health problems they were

experiencing, before getting a referral to a neurologist more people were now only seeing their GP once before getting a referral than in 2016 (up by 7%). However, 36% were still seeing their GP more than three times before getting a referral (diagram 1).

**“WITH THE NHS [I] WAS JUST BEING FOBBED-OFF. THEY WERE SAYING I HAD ANXIETY, DEPRESSION AND INSOMNIA CAUSED BY THE DEPRESSION, ARTHRITIC KNEE CAUSING LIMP AND LEFT FOOT DRAGGING. HENCE THE ONLY OPTION I HAD WAS TO GO PRIVATE TO FIND OUT EXACTLY WHAT WAS THE PROBLEM, AS I KNEW IT WAS NOT CORRECT WHAT THE GP WAS SAYING.”**

#### DIAGRAM 1

Before you were told you needed to be referred to a neurologist, how many times did you see your GP (family doctor) about the health problems you were experiencing?

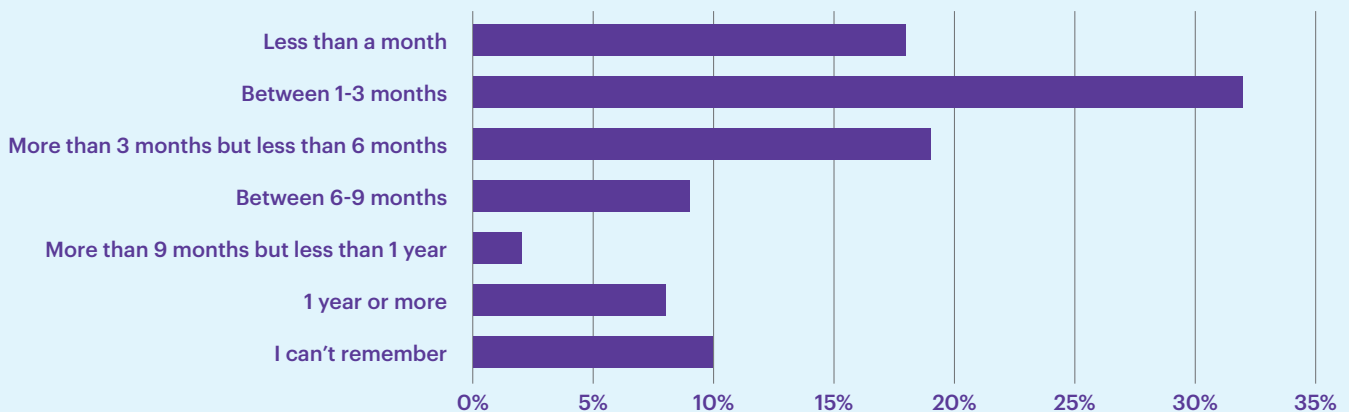


### SPEED OF ACCESS OF NEUROLOGISTS

The speed at which neurologists can see people and then whether they are making the right diagnosis is the second issue. Half of the people see a neurologist within three months but conversely some (c. one in ten) wait more than nine months (diagram 2).

#### DIAGRAM 2

How long was it before you were seen by a neurologist, following your referral?



### SPEED OF ACCESS OF NEUROLOGISTS

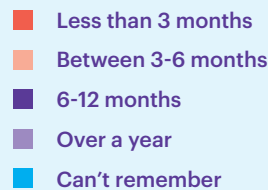
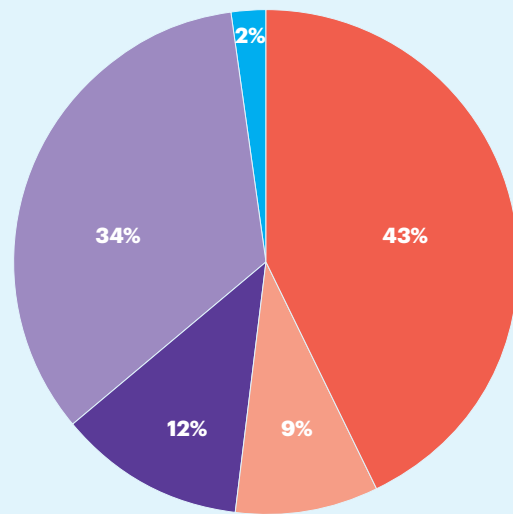
For one in three people, it still takes over a year from first seeing the neurologist to getting a confirmed diagnosis of PSP or CBD.

It is easy to see how all these delays add up to the average time to get a diagnosis of PSP or CBD being three years.

Nearly 60% of patients are incorrectly diagnosed in the first instance but more people now seem to be diagnosed with Parkinson's rather than other conditions.

**“FROM INITIALLY REALISING SOMETHING WAS WRONG TO HAVING A CONFIRMED DIAGNOSIS WAS TWO YEARS. SINCE FINALLY BEING DIAGNOSED, ADDENBROOKS HAS BEEN BRILLIANT.”**

### TIME TO DIAGNOSIS FROM SEEING A NEUROLOGIST



### CORRECT DIAGNOSIS

2022 2016



**“AFTER A YEAR, I HAD TO PROMPT THE CONSULTANT TO GET ME A SCAN AS THE PARKINSON’S MEDICATION WASN’T WORKING. HE REFERRED ME TO A NEUROLOGIST AND I HAD AN MRI AND PET SCANS AND THE NEUROLOGIST CONFIRMED THAT I HAD PSP. HOWEVER, THREE WEEKS LATER MY CONSULTANT TOLD ME I HAD A SEVERE FORM OF PARKINSON’S. I ASKED FOR A PHONE CALL WITH MY GP, WHO CONFIRMED THE PSP DIAGNOSIS.”**

The results of the survey demonstrate the pressing need to raise awareness of PSP & CBD with health and social care professionals to improve the speed and accuracy of diagnosis. This is one of PSPA's strategic goals.

We believe, together we can improve diagnosis for the 10,000 people living with PSP & CBD, saving time, resources and helping patients to get the care they need faster.

**PSP**