

# PSP **MATTERS**

CREATING A BETTER FUTURE FOR  
PEOPLE LIVING WITH PSP & CBD

AUTUMN 2022



## ALSO INSIDE

**SUPPORT GROUP  
UPDATES**

**VOICE BANKING**

**LEAVING A GIFT IN  
YOUR WILL**

**RESEARCH  
LOOKING FOR EARLY  
BIOMARKERS**

**RECRUITING FOR A STUDY  
LOOKING INTO PSP**

# WELCOME



**With winter coming I am sure some of you are concerned about the impact of the cost-of-living crisis. We understand that for many the costs of things like heating and charging electric wheelchairs can be an increased cost when you are living with an illness. Whilst there are no simple solutions it is important to check you are**

**getting all the financial support you are entitled to. I would urge anyone who thinks they may struggle with their energy bills to get in touch with their energy supplier to ask how they can help. You may be entitled to a grant, and you can certainly ask to be put on the priority services register. This is a free service to help people in vulnerable situations.**

Over the summer I have enjoyed meeting people at local Support Groups with in-person visits to the Isle of Wight and Durham. Carers and volunteers' passion and commitment shone through as did the sense of community and companionship created by everyone attending the groups. In addition, I was also able to visit Dr Boyd Ghosh's clinic in Southampton, I am very grateful to those patients who let me sit in on their consultations and for all the time Boyd took to explain how the clinic works. It was a valuable experience in learning about the challenges of making a diagnosis and how care can be improved through a multidisciplinary team approach. I have more visits scheduled over the coming months to continue to learn about people's experiences, their priorities for PSPA and to get feedback on our services.

I attended the first Research Involvement Group meeting, where five volunteers started the process of learning how they can be involved in the design

## LEAVING A GIFT IN YOUR WILL IS A QUICK AND EASY WAY TO SUPPORT PSPA.

**By having a Will, you can give peace of mind to loved ones, and ensure all of your wishes are met. A gift in your Will is also a generous way of giving, which doesn't affect you in your lifetime. It can however, have a huge and lasting impact for PSPA, enabling us to invest in research and support families living with PSP & CBD.**

This year PSPA has teamed up with Farewill to trial a new Will scheme. Farewill is the largest Will writer in the UK and very well recognised for their quality of customer care and attention to detail.

By taking part in this trial, you are under no obligation to leave a gift in your Will to PSPA, but we would be delighted if you would consider it. To find out more, please contact Farewill on **020 8050 2686** or visit **[farewill.com/pspa-autumn22](https://farewill.com/pspa-autumn22)**

of research. I hope that this group will grow and will help shape research priorities and design for the future. They will be instrumental in helping to plan the next research day in February 2023. With recruitment to the new Services Committee underway we are on the way to greater involvement in and a stronger voice for people living with PSP & CBD.

The number of returns from the patient survey is promising, by the end of the year we will have a bank of data that helps us to raise awareness and improving our capacity to influence for change. Thank you to everyone who has taken the time to complete the survey.

In this edition of PSPA Matters you will find practical information on social care assessments, ideas for fundraising and news about the new research fellowship we are sponsoring in partnership with the Association of British Neurologists (ABN), alongside a host of other articles. I hope you all find something that is informative, we are always open to suggestions for articles and how the magazine can be improved.



**Rebecca Packwood**  
PSPA CEO



**For more information**

**call 020 8050 2686**

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### PLACE A PSPA COLLECTION TIN IN YOUR AREA

A simple, effective way to support PSPA is by placing collecting tins in your local community. Hosting a collection tin is a brilliant way to raise funds and awareness for the charity.

These can be placed in local shops and cafes, office receptions, clubs, restaurants and pubs. In fact, they can be placed pretty much anywhere! Just ask the business owner or responsible person's permission and fill in a simple form.

Can you help? To find out more or request a tin please contact the fundraising team on **01327 322414** or via **fundraising@pspassociation.org.uk**.

### ABN RESEARCH FELLOWSHIPS

This year, PSPA is pleased to team up with the Association of British Neurologists (ABN) to provide a two to three-year Fellowship.

With these Fellowships we aim to support the rising stars in research. We have partnered with the ABN to support a pre-consultant level neurologist to obtain a higher degree (PhD, MD) in research focused on neurological disorders with clear benefit to patients. The award will cover salary and research consumables. PSPA will be part of the process of selecting the best project ideas and identify one clinician to support. More information can be found at **[www.theabn.org/page/Fellowship-Application-2023](http://www.theabn.org/page/Fellowship-Application-2023)**



### SAVE THE DATE - RESEARCH INFORMATION DAY 2023

Following the success of our 2021 event, PSPA is excited to announce our second online Research Information Day on Friday 3 February 2023.

During the day, we aim to bring up to 300 virtual attendees together, be they people living with PSP or CBD, carers, researchers and health professionals, to share knowledge, answer questions and raise awareness of PSP & CBD.

A draft programme will be available on the PSPA website later this year. Registration is free and open in December.

### PSPA THE POWER OF THE BRAIN QUIZ

This autumn, PSPA will be launching our own quiz, the Power of the Brain!

This is a brand-new fundraising activity for all, a general knowledge quiz to challenge you and your friends, whether you play virtually or in person.

The Power of the Brain will bring friends, family and colleagues together to raise money to help improve the lives of everyone affected by PSP & CBD. So, get your thinking caps on!

More information will be coming soon!



### SUPPORT GROUP MEETINGS IN WALES

If you live in Wales and would like to connect with people living with PSP & CBD in your area, you can join a Support Group at a meeting soon:

#### North Wales

13 December at 11am via Zoom

#### South Wales

18 October at 11am via Zoom

15 November at 11am via Zoom

We are currently recruiting for more volunteers to become Support Group Coordinators in South Wales. If you would like to help support people living with PSP & CBD in your area, get in touch at [volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk)

### HELPING YOU WITH THE COST OF LIVING CRISIS

With soaring energy bills dominating the media, it's all too easy to despair. But there are schemes available to help, including a one-off Disability

Cost of Living Payment and the British Gas Energy Trust. We've pulled together some useful information on our website at [www.pspassociation.org.uk/news/helping-you-with-the-cost-of-living-crisis/](http://www.pspassociation.org.uk/news/helping-you-with-the-cost-of-living-crisis/)

The PSPA Helpline is also available to guide you towards the most up to date information and support available. Get in touch at **0300 0110 122** or [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)



### PSPA'S 2022 CHRISTMAS RANGE

You will see from the enclosed Christmas card catalogue that our 2022 Christmas range is now available!

We've gathered a fantastic selection of cards to help you raise vital funds and awareness.

These can be ordered by completing the enclosed order form or by visiting our PSPA shop: [www.pspassociation.org.uk/fundraising/shop/](http://www.pspassociation.org.uk/fundraising/shop/)

### IF YOU WOULD LIKE TO SUPPORT OUR WORK, THERE ARE MANY WAYS YOU CAN MAKE A DONATION TO PSPA.

- Phone – call **01327 322414**
- Text – text **TEAMPSPA** to **70085** to donate **£5**
- Set up a regular gift online [www.pspassociation.org.uk/fundraising/donate](http://www.pspassociation.org.uk/fundraising/donate)

Every penny you give will make a difference to people with PSP & CBD, their carers and family. Your donation will fund our information and support services and will be invested in research into PSP & CBD.





## NEW FACES AT PSPA

We welcome two new members staff to the PSPA team in the last few months. Here, our new team members introduce themselves.



**BECCA LEATHLEAN – COMMUNICATIONS ASSISTANT**

Hello! I’m Becca and I joined PSPA in July after seeing the Communications Assistant job on the website. A friend of mine had just been diagnosed with PSP and I was seeking information.

I have a background in journalism, writing for magazines and broadsheet newspapers. I also worked for Save the Children, editing a supporters’ magazine, and another charity, the Thames Valley Partnership, where I had a brief to promote alternatives to prison. After that, I ran my own business for several years, only recently returning to the world of communications – a world which has changed quite a bit since I was away!

I’m thrilled to be here and I can’t wait to help promote everything the charity does as well as spotlighting the amazing staff, volunteers, donors and fundraisers who work together to make this possible.



**MAYA KEMP – HEAD OF FINANCE**

I was pleased to join the PSPA team this summer.

I am an experienced Finance Manager and have worked in various industries from manufacturing, travel and tourism and healthcare.

In my spare time I am studying Criminology and am a keen photographer too.

I am looking forward to working with the team, and PSPA supporters and hope I can use my experience to make a real difference at the charity.



# PEER SUPPORT FOR YOUNG PEOPLE

In September 2020 we launched the Youth Support Group with the help of PSPA volunteer Kathryn Embree. The group has grown from strength to strength since it's launch, to provide essential peer support.

"I was sixteen when my father was diagnosed with PSP and I had no idea what that was, what that meant or even what to ask. Of course, there was no reason I would know, most adults aren't aware of PSP & CBD, let alone someone doing their GCSE's!

Several years later, during the first lockdown of 2020, I began wondering about other young people who were going or went through the same thing I did. I thought about how helpful I would have found a group of people my age to talk through and discuss what was happening to our parents, grandparents and loved ones; this is when I reached out to PSPA and the Youth Support Group was born.

Since then, the group has met monthly and has grown year on year. It is held completely online, which means anyone from across the country and beyond (we have international members!) can join. The meetings range from specific talks, to generally catching up about our lives over the last month. There is a real sense of friendship and comradery in the group which I'm incredibly proud of.

There is no pressure to attend every meeting; it is there as a resource and members should never feel the burden to attend. Of course, many of our members are carers and so can't necessarily give up an evening every month, which we completely understand. Due to this we also have an active WhatsApp group, so that in-between meetings people can reach out to share frustrations, ask questions and generally have a network of support on hand if they need.

To join the group, you do not need to be a live-in carer, you are also more than welcome to join if you have previously lost a loved one to PSP or CBD. Generally, we recommend that members are aged between 16 and 30 years old, but we are putting



together a group for under 16s, so if you have a child that would like to be involved, please do get in touch.

This group is a network and many friendships have been born from it. It allows you to be completely honest and not have to explain life with a loved one with PSP or CBD, because we understand.

If you would like to join, know a young person that you think would benefit from the group or just want some more information please do get in touch at [volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk) or call **01327 356136**.

## UPCOMING MEETING DATES:

Wednesday 26 November 7pm  
Sunday 13 December at 6.30pm



## A RUN FOR OUR NAN

Nan, Marilyn Whittaker, was diagnosed with PSP in 2019 after experiencing symptoms for 12 months. Here, Marilyn's grandchildren share details of their nan and why they came together as a family to complete the Liverpool Half Marathon in her honour.

"Our Nan, Marilyn, was a lovely lady with a big heart. She is a mum to two daughters (Joanne and Claire) and a Nan to seven Grandchildren (James, Elliot, Mia, William, Thomas, Harry and Ted). She is a massive part of all our lives.

Nan was diagnosed with PSP in 2019. However, we had been noticing changes in her 12 months prior to that. Usually a very independent, sociable lady, Nan became quite withdrawn, refusing to go out unless accompanied by one of the family. She lost confidence in her own ability resulting in her giving up driving. She also became confused and quite obsessive about certain things and unfortunately experienced several minor falls.

Shortly after her diagnosis, Nan had two serious falls which resulted in lengthy hospital stays. It was

after the last stay in hospital she was transferred to a rehabilitation centre and it was whilst she was there that her house flooded, and she was admitted to temporarily respite care whilst it was made habitable. Sadly, within two weeks of her being in respite care lockdown came into force and as a result Nan lost what skills she had to live independently. It was one of the hardest times for us as a family as we were only allowed limited, non-contact visits through a window. It was over 12 months before we could finally hold her hand again.

Over time, her condition deteriorated with Nan's eyesight worsening as well as her struggling to swallow food and drink. As well as this, her physical condition declined with Nan eventually requiring a wheelchair. Nan's condition progressed quite rapidly and in February she was given 24 hours to live.





However, that was five weeks prior to her passing as Nan's love shone one last time for us and she fought to stay with us to reach the day of our race.

Nan passed away in the early hours of the 27 March, Mother's Day, which was also the day of the Liverpool half-marathon. Despite losing our precious Nan, we all decided to still run in her honour and as a family we were there together.

PSP is a very rare condition which we were not aware of ourselves until Nan's diagnosis. At the time, we were unaware of the extent of the condition, and as Nan's condition worsened it really hit home as to the seriousness of PSP. As a family we felt it was important to show Nan we were supporting her, as well as raising awareness and funds for PSPA. The half marathon aka 'A Run for Our Nan' was something we could all complete.

The training involved lots of long runs throughout winter on cold, dark and rainy evenings. Some of us had setbacks which involved injuries, and a few

certainly got sick of the training regime. James unfortunately was unable to train in the four weeks prior to the run as he tore his intercostal muscles in training. Despite this, we knew it was nothing compared to what Nan was experiencing and she made sure we kept going throughout the training, asking us how we were getting on and how the fundraising was going.

The actual half-marathon itself went really well for all five of us and strangely enough Nan passing a few hours earlier spurred us on to finish. It was a real adrenaline rush completing the challenge in front of hundreds of people, whilst wearing our PSPA t-shirts. As a family we were all there together, some of us running (the hard part) and some of us cheering on. We all knew that Mum and Dad/Nan and Grandad were watching over us with immense love and pride. We hope to do more fundraising in Nan's memory in the future."





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## **FINDING YOUR WAY THROUGH THE MAZE ... SOCIAL CARE ASSESSMENTS**

Whether you need some help to care for yourself, or a loved one or to make changes to your home so it is more suitable for your needs, your starting point should be Adult Social Care.



Adult Social Care is an umbrella term, used to describe services, adaptations, and equipment provided when extra support is needed to maintain independence, dignity and safety. Individuals who may support you with social care could include a social worker, an occupational therapist (OT) a physiotherapist or professional carers.

It may be that you have spent some time in hospital, or you and/or your carer, who may be your life partner, or a family member/friend are finding you need more support. Under Law, The Care Act 2014, you are legally entitled to a Care Act assessment/ review or a Carers assessment/review.

### HOW DO I ACCESS SOCIAL CARE?

You need to contact your local council (where you pay your council tax) and speak to the Adult Social Services Team. Certain councils may have a 'contact us' link/email address on their website. They will ask a few questions to gain an understanding of your situation, to determine the urgency and to see if they are the most suitable service, if not they should signpost you (where possible). Following your contact they will either arrange for assessment as soon as possible (if urgent) or allocate you to a social worker to arrange the assessment.

### WHAT SERVICES, ADAPTATIONS AND EQUIPMENT ARE AVAILABLE?

Services may include care within your own home, support to socialise/access your community, respite, meals on wheels, personal alarms, and support to move into a care/nursing home. Support for carers may include carer breaks and support to continue to do the things that matter to you. Carers support looks different for everyone as it is shaped to enhance your life as a carer.

Adaptations to your home where possible, may be necessary for you to be able to live there safely. Adaptations can be big for example installing a lift, a wet room, or a wheelchair ramp. They can also be small such as installing rails or bath seats. Some councils may pay for adaptations costing less than £1,000. For larger adaptations you can apply for a Disabled Facilities Grant (DFG), this is means tested, your social worker or OT will explain how this works, more information can be found here- [www.gov.uk/disabled-facilities-grants](http://www.gov.uk/disabled-facilities-grants)

### WHAT DOES AN ASSESSMENT LOOK LIKE?

There are two types of assessment: Care Act Assessment and a Carers Assessment, both have

yearly reviews if services are put into place. It is important to be honest throughout your assessment and reviews and to answer questions based on what your care needs are on a bad day.

A care assessment is a person-centred look into how you manage everyday life. It will highlight if you are eligible for services or not. It focusses on 10 aspects of your daily life, however if you feel something else is important then please share it.

- Managing and maintaining nutrition
- Personal care
- Toileting
- Being appropriately dressed
- Staying safe in your own home
- Maintaining relationships with family and friends
- Accessing work, volunteering, training, or education
- Accessing local services and your community
- Looking after others
- Maintaining your own home.

To be eligible for care and support you must require help with two or more of the above.

Before your assessment, you may find it helpful to make notes of all aspects of daily living you feel you would like/need support with, any questions, medications and what they are for and any equipment you feel may help. You may find it supportive to have someone with you.

A carers assessment is for anyone who is over 18 years old who cares for someone who is disabled, or ill. You do not have to live with the person, and you will not be financially assessed. Prior to assessment it may be helpful to keep a diary or write a list of everything you do within your caring role.

The assessment will look at the following aspects and consider how/if your caring affects/prevents you from achieving them.

- Managing caring responsibilities for children and/or another adult
- Maintaining a habitable home
- Managing and maintaining your nutrition
- Developing and maintaining family relationships
- Engaging in work, training, education, or volunteering
- Accessing necessary facilities or services within your community
- Engaging in recreational activities.

You are eligible if any of the above impact on your wellbeing physically or mentally and/or you are

finding it challenging due to your caring role to achieve any of the above.

**WILL I HAVE TO SELL MY HOUSE?**

If you are eligible for care and support, the assessor will discuss this with you and create with you, your care and support plan. It will detail what your eligible needs are and how they will be met, and costs of the support provided.

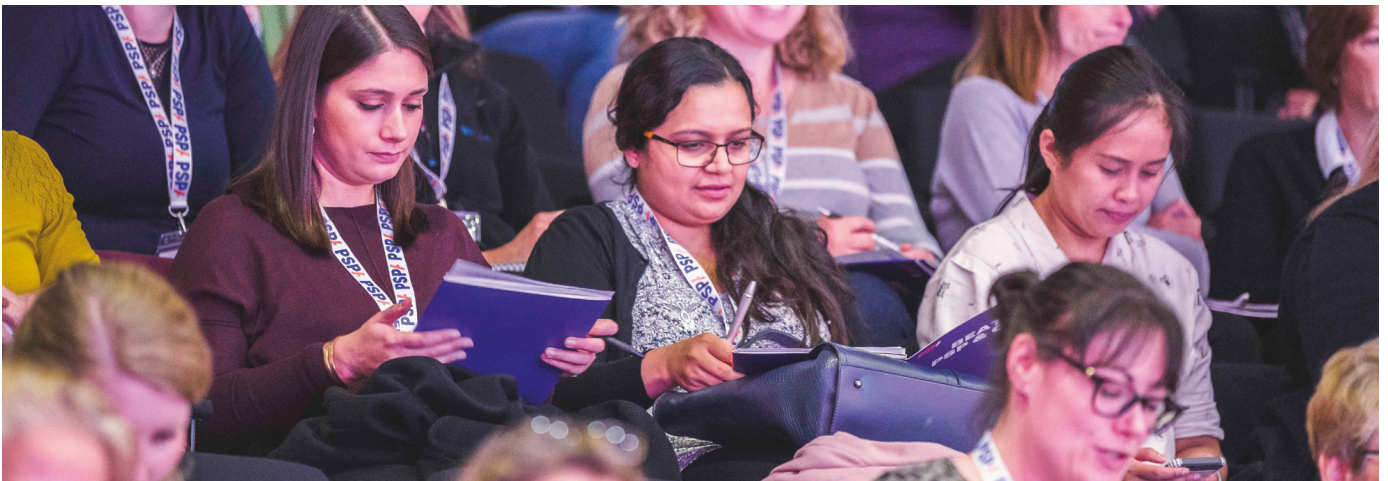
Social care isn't usually free. To decide how much, you may have to pay towards the cost of your care and support, the council will assess your income and capital (usually in the form of savings). This is known as the financial assessment or means test.

The value of your home isn't considered if you need care in your own home. If you own a second property, the value of this will be included in your financial assessment.

Up to date information regarding financial assessments can be found here- [www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/financial-assessment-means-test/](https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/financial-assessment-means-test/)

The information provide in this article is applicable to people living in England and Wales. Different rules may apply in Scotland and Northern Ireland. Please contact the PSPA Helpline for further information.





## 2022 PSPA STUDY DAY

We are pleased to announce details of our 2022 online Study Day for Health and Social Care Professionals.

We are pleased to confirm the return of our well-attended Study Day for healthcare professionals.

This free event is taking place on Friday 21 October, 10.30am to 4pm via Zoom.

The Study Day will look at clinical presentation of the two conditions. The signs and symptoms will also be explained in more detail with a focus on management.

In addition, you will hear about the latest research and the work of PSPA.

If you are supporting people living with PSP & CBD or just want to know more, then this is the event for you.

Register for free at [www.eventbrite.co.uk/e/pspa-virtual-study-day-2022-tickets-415179040687](https://www.eventbrite.co.uk/e/pspa-virtual-study-day-2022-tickets-415179040687)



## IMPROVING DIAGNOSIS AND CARE IN PSP & CBD

Dr Diane Swallow is a Clinical Lecturer in Neurology at the University of Aberdeen. She undertook a three-year research fellowship in Scotland, jointly funded by PSPA and the Scottish Chief Scientist Office. In this article she provides an update on the findings from this research to date.

For many people with PSP & CBD, their journey towards receiving a diagnosis was a long one, occurring many years after their first symptoms began, and often came after they were initially diagnosed with a different condition like Parkinson's. Improving our ability to provide an accurate and timely diagnosis is of huge importance, enabling those with PSP or CBD and their families to plan ahead and best manage the condition.

We also need to know more about how PSP & CBD practically affect day to day function over time, the sort of multidisciplinary care or aids people may require and when, so that we can better anticipate the support both individuals with PSP & CBD, and their families, will require at all stages of the illness. Identifying and counting all people living with PSP & CBD in a particular geographical area (called prevalence) is information which is essential for the planning, delivery and use of health services.

### WHAT DID WE DO?

#### 1. Successfully established a new Scottish cohort of individuals with PSP, CBD and their caregivers to investigate diagnosis and care

People with PSP & CBD participating in this cohort consented to: (i) access to medical records and data linkage; (ii) inclusion in a Scottish PSP & CBD register; (iii) a one off in-person assessment including measures of motor function, memory/thinking, mood, quality of life and ability to undertake daily activities; (iv) postal six-month follow-up assessment, (v) baseline and six-month MRI brain scan, (vi) brain donation. Caregivers were also invited to evaluate their family members abilities, complete assessments on their own health status and carer input.

#### 2. Determined a new prevalence rate for PSP & CBD in Scotland

We established a new prevalence study which used multiple overlapping methods of case finding



including hospital clinician referral, GP referral, self-referral, Scottish Morbidity Record ICD-10 diagnostic code searches, and searches of outpatient letters in key specialties to find and count the number of people living with PSP & CBD in Scotland.

### 3. Evaluated diagnostic pathways from symptom onset in PSP & CBD

In the newly established Scottish PSP & CBD cohort, both people with PSP & CBD, and their caregivers, reported key diagnostic milestones from symptom onset. Diagnostic pathways were also evaluated in an existing study in the North-East of Scotland, the Parkinsonism Incidence in the North-East (PINE) study, by chronologically and systematically hand searching the medical records of each person with PSP & CBD recruited to this study, comparing diagnostic pathways to people of the same age and sex with Parkinson's disease.

#### WHAT HAVE WE FOUND TO DATE AND WHAT DOES IT MEAN? - Diagnosis

Comparing individuals with PSP & CBD to those of the same age and sex with Parkinson's disease in the PINE study we showed that:

- Individuals with Parkinson's receive their final, unchanging diagnosis from their first symptoms in approximately one year while for those with PSP & CBD final diagnosis is approximately four years after symptom onset
- Individuals with PSP & CBD are less rapidly referred to secondary care after symptom onset than those with Parkinson's which leads to more emergency hospital attendances with a lengthier period of hospitalisation before people receive their diagnosis. Hospitalisation does not speed up diagnosis, nor does it reliably trigger outpatient referral to relevant specialties which for some leads to recurrent emergency admissions
- There is a greater tendency within primary care to misattribute relevant symptoms in people with PSP & CBD to alternative diagnoses, resulting in a wide secondary care referral pattern to non-movement disorder specialties. Specialist input is essential as, unlike people with Parkinson's disease, individuals with PSP or CBD are rarely diagnosed prior to this input
- Even after specialist input, diagnosis is still difficult. Approximately 50% of those with PSP & CBD are diagnosed at their first specialist assessment, reaching approximately 75% by their final review.

Diagnostic delay has unfortunately not improved significantly over a decade. The time to diagnosis

reported by individuals with PSP & CBD participating in the new Scottish PSP & CBD cohort was similar to findings from the PINE study.

#### Prevalence

The most reliable data from the Scottish PSP & CBD prevalence study shows that approximately four in every 100,000 people have PSP, while approximately two in 100,000 people have CBD. PSP & CBD are most common in those aged 70 to 79 years. Due to multiple different clinical presentations, misdiagnosis and delayed diagnosis, these numbers are likely to be underestimates. In an aging population the numbers of people with PSP & CBD are also likely to increase.

#### WHAT IMPACT COULD THESE FINDINGS HAVE?

- Applying the information we have gathered on weaknesses in the diagnostic process will help us target key preventable and reducible sources of diagnostic error to shorten diagnostic delay
- This will help us develop evidence-based, specific and measurable referral and diagnostic targets for use by doctors and other healthcare professionals
- A greater understanding of the number of people living with PSP & CBD in Scotland will inform the planning of health services and allocation of resources.

#### WHAT'S NEXT?

Analysis of the data collected from the PINE study and Scottish PSP & CBD cohort is ongoing. We will describe people's experience of their diagnostic journey and assess whether new scales or imaging techniques could be used in clinics to improve diagnosis. We will evaluate care pathways to find out whether PSPA's Care Pathway is being followed, and if not, which areas need improvement. We will also assess how people with PSP & CBD (and their caregivers) fare over time so we understand more about their health needs and assess new ways of measuring disease progression to help in future treatment trials. I look forward to updating you as we continue to learn more about these important aspects of diagnosis, prognosis and care.

Attempting to make inroads in answering any of these questions would have been impossible without the partnership of individuals with PSP & CBD and their families- the true experts in these diseases. We are thankful to individuals previously recruited to the PINE study and, more recently, those from across Scotland who, by openly sharing their personal experience of PSP or CBD and in giving so much of their time and energy, offer hope to those who will tread the same challenging pathway after them.

# FUNDRAISING AT WORK AND IN YOUR LOCAL COMMUNITY

Fundraising is hugely important for the vital services that PSPA provides. Here James Holden, PSPA's Community and Corporate Fundraising Manager, helps to breakdown and explore how you can help fundraise at work and in your community.



## COMMUNITY FUNDRAISING

"Community fundraising is the heartbeat of our charity, and our amazing supporters and volunteers raise us hundreds of thousands of pounds annually in all sorts of incredibly powerful ways.

There are endless ways to fundraise in your community. However you want to fundraise, whatever idea you have, it can be supported and used to inspire people to donate to PSPA.

Here is a quick (and certainly not exhaustive) list of brilliant fundraising activities to get you inspired to fundraise in your community:

- Have a garden sale or host a horticultural competition
- Host a bake sale
- Hold a Facebook fundraiser
- Go booze free for a set time
- Organise a coffee morning at your local social club or village hall
- A skills auction; discover peoples' hidden talents
- A head shave
- A book sale
- Organize a quiz or games night

- Fancy dress
- Host a summer (or winter!) BBQ
- Bingo or dance night
- Yoga sessions or a zumbathon.
- Involve your family, children and grandchildren: hold a school fete, dress up for world book day, guess the number of sweets in a jar, or speak to their community and sports clubs.

Two of our supporters, Linda and Nerissa have recently completed community fundraising for PSPA, and we are so grateful.

Linda and the Norwich Support Group hosted a 'Gastonbury' fundraising festival, with music and food. They raised over £500 selling cakes, a raffle and merchandise!

Nerissa hosted a yoga and awareness event called 'Yoga in the Park' and despite the rain on the day, raised over an incredible £270."

## CORPORATE FUNDRAISING

Corporate fundraising is frequently used as an umbrella term for all the money raised from companies for charities. It is also a term used by businesses to describe when they fundraise on behalf of a charity using their employees or customers.

Partnership with companies and businesses can bring many benefits to our charity, providing funds as well as brand awareness, expertise and gifts in kind. In the last issue of PSPA we discussed Talbots and their partnership with us.

Corporate fundraising can include all of these:

- Staff fundraising





- Charity of the Year
- Supplier fundraising
- Payroll Giving
- Networking groups
- Donations/matched giving
- Employee involvement and volunteering
- Cause-related (where businesses and charities form a partnership for mutual benefit)
- Sponsorship
- Amazon Smile
- Gifts in kind
- Collection tins
- Events
- Recycling opportunities.

Our relationships with businesses, small or large, are vital in developing awareness and raising funds for PSPA and are a great catalyst for future conversations and fundraising.

Something that can tie these forms of fundraising together are collection tins! These can be placed almost anywhere and are a powerful awareness and fundraising tool. To find out more, please have a look at page 4.

Both Community and Corporate Fundraising are also not possible without you, our wonderful supporters. So, thank you for everything you do for PSPA!



**A FUNDRAISING TAKE OVER OF WREN HALL**

As an experienced Volunteer Support Group Coordinator, Jenny Knight is used to organising meetings and activities for PSPA. Two years ago, Jenny found she could use her skills to not only support local people but fundraise for PSPA too.

“In November 2018, while preparing for our meeting at Kenilworth Methodist Church, two men walked through the kitchen. They enquired about what we were doing, sampled our cakes, made a donation and said, “have you ever thought about applying for a slot at Wren Hall?”

I learned that Wren Hall, in Wroxall near Warwick, is a village hall where every Sunday afternoon in the summer local charities run ‘Sunday Tea and Cake’ events. It is very popular with local people, some coming most weeks to meet up with friends.

I applied and the Coventry and Warwickshire Support Group were allocated Sunday 6 October 2019. Then I needed to find nine volunteers and 25 homemade cakes!

I saw the event more as an opportunity to raise awareness of PSP & CBD rather than lots of money. It was a very successful afternoon and we raised £430 as well as lots of awareness.

We are only a small group, but everyone contributed in some way. The afternoon was tiring but enjoyable and at the end volunteers were heard to say, “Are we doing it again next year?”

Unfortunately, because of the Covid-19 pandemic, next year became 25 September this year. This was another successful event, raising £500.50 and exploring even more conversations about PSP & CBD.”

**GET INVOLVED**

If Jenny’s event has inspired you and you would like to explore options for fundraising in your local area, our fundraising team can help! Get in touch at [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk) or call us on **01327 322414**.



## A DAY IN THE LIFE OF A SPEECH AND LANGUAGE THERAPIST (SLT)

As part of our ongoing 'Day in the life' features, Caroline Jeffries-Shaw, principal speech and language therapist at Croydon University Hospital, Croydon Health Services NHS Trust, shares details of her career and current role.

"I graduated in 1996 from The Royal Central School of Speech and Drama with my degree in Speech and Language Therapy. My first job was in Croydon and was a split post, working with both adults and children. However, I quickly realised that I preferred working with adults and, in particular, those who had a neurological condition. In 2000, I was appointed to a post at The National Hospital for Neurology and Neurosurgery in London. It was during this post that I was exposed to the rarer neurological conditions, which included PSP & CBD.

I have returned to Croydon several times during my career and currently I am the principal speech

and language therapist who has a specialism in progressive neurological conditions. I have held this post since 2016 and the part I enjoy most about my role is working across both outpatients and community (home visits) settings. This environment enables me to build a relationship with a person who has been recently diagnosed and maintain that relationship with both the client and with their loved ones throughout their journey.

My day varies hugely day by day. I usually start around 8am with coffee and some time for emails and general admin. I network with a range of other professionals via email such as gastroenterologists,



neurologists, dietetics, Parkinson's nurse specialists, physiotherapists and occupational therapists. As part of my role, I am involved in delivering training to other professionals both informally and via formal presentations. This involves talking to a range of professionals including nurses, doctors and health care assistants regarding when to refer someone to Speech and Language Therapy and the types of difficulties with which we may be able to assist.

When working with someone with PSP or CBD, I am usually involved in assessing and facilitating their communication as well as their swallowing function. Communication work involves assessing how someone is able to communicate at present and suggesting ways of helping this to be more reliable and efficient with their carers and loved ones. The relatively recent development of voice banking has meant that people can now opt to bank their voice early in their diagnosis; this can then be used in the future on a communication aid, rather than using a computer generated voice. I discuss this option with my clients as early as possible in order to help them decide if this is something that they would like to do. The process is relatively quick now and can often be completed in one session. I work closely with PSPA during this process, as they may be able to provide assistance with funding of this. Sometimes a referral is required to our local specialist AAC (Alternative and Augmentative Communication) hub. However, it is always important to provide a low-tech option as well, which someone can use to facilitate communication; this may be in the form of a personalised communication book or simple charts that cover basic needs and a 'Yes/No' option.

When assessing a client's swallowing, I usually work closely with my colleagues in dietetics. My role is to assess which textures and fluids are safest for someone to tolerate. The aim is to optimise a client's hydration and nutrition needs, as well as reducing the risk of aspiration. Aside from assessing someone with various food textures and fluids, I sometimes also request an instrumental assessment of their swallowing. This will be either via videofluoroscopy (a moving x-ray image) or via FEES (fibre optic endoscopic evaluation of swallowing). These methods of assessment also help to provide my client with visual feedback about their swallowing which can help them make decisions about how they may wish to manage their swallowing difficulty (dysphagia). I will then discuss with the client and their family/carer regarding whether they wish to

be considered for alternative feeding options such as PEG or RIG as well as the potential timing for this referral.

As part of my role, I often attend multidisciplinary meetings with a range of other professionals who have experience of working with a similar caseload. This enables me to discuss and problem solve issues for a client that may not necessarily be within my remit as a Speech and Language Therapist. For instance, I can link with my colleagues in social services regarding advice relating to benefits that may be available to someone. My physiotherapy and occupational therapy colleagues provide valuable suggestions regarding positioning for my clients, which can be beneficial in terms of supporting them for eating, drinking and communication. During COVID, our meetings switched to Zoom/MS Teams and this has meant that more people can attend, which has to be a benefit of the pandemic!

As a senior member of the SLT team, I am available to other team members for clinical supervision and case discussions. I enjoy talking through cases with my colleagues and sharing ideas and resources.

Finally, a large part of my role is to support my clients and their families during their journey with a PSP or CBD diagnosis. I strive to provide a listening ear and to facilitate helping them adapt to the changes that lay ahead. I try to provide them with the information they need in order to adapt to the future whilst being sensitive to their wishes. I believe my role is to be there for the person with PSP or CBD as well as their family and carers, as this type of condition can have an impact on the whole family.

As I also volunteer for PSPA on their evening Helpline, I am, I think, one of the original group of volunteers from 2014; this means that approximately twice a month I am available to support people who are facing the challenge of PSP & CBD. Through this connection to PSPA I have had the opportunity to meet many people who have experience of PSP & CBD and I have valued learning from them."

# BANKING YOUR VOICE WITH PSPA AND SPEAKUNIQUE

In February 2012, we launched a Voice Banking Service in partnership with SpeakUnique. Since the launch, this service has helped more than 35 people maintain their communication. Here Sue Connolly and Colin Shearsmith share their experience of banking their voice and the impact it's had on their lives.



## SUE CONNOLLY

"I had been ill for a few years and had been back and forth to my GP a fair bit. I knew something wasn't right but at first, I was diagnosed with stress, then depression.

I knew I wasn't depressed but it felt like a bit of a battle to be completely heard. Walking began to make me feel like I was drunk on a boat, with the ground constantly moving. So, I persisted and kept going back until in November 2020 I was diagnosed with Parkinson's.

As my symptoms progressed, my diagnosis was changed to PSP in December 2021. The Neuro team helpfully put me in touch with PSPA. I joined my local

PSPA Support Group, which is where I heard about the PSPA Voice Banking Funding.

One of the carers mentioned it earlier this year. Unfortunately, her husband's voice had deteriorated too much to access the service, but she encouraged me to look into it. Although my voice is weaker in the afternoons, I can still speak well in the mornings. I liaised with my speech and language therapist (SLT) who successfully applied for the funding on my behalf.

After I had received the funding, my SLT put things in motion with SpeakUnique and she also ordered a Smart Box (tablet type device) for me to use. When the Smart Box came, my SLT came around and set it all up for us and helped to show me how to use it.

Since February 2022, physically I have not been as strong. As well as affecting my walking and balance, I have also been unable to use my dominant right hand. I now use my left hand. I'm still quite slow typing on the Smart Box with my left hand which is really frustrating as I used to touch type.

Once I knew my way around the Smart Box I set to work with recording my voice. The process was quite easy. I recorded around 300 sentences, this was around 15 sentences a day, so overall it took a couple of months to do the whole recording process.

I purchased a set of headphones with a microphone attached to help with recording my voice. The clarity of the recordings was pretty good.

You do get a choice of books to read from. There's a good selection, everything from Peter Rabbit and Harry Potter, to Sherlock Holmes and Jane Austen.



I love Jane Austen so initially picked one of those books but the length of sentences and style of writing made it quite difficult to read aloud from so I then swapped to Peter Rabbit.

Once my voice recordings were completed and ready to be used I experienced mixed emotions. I know it will help in the future when my voice becomes weaker, but it is strange hearing your voice back and I don't 100% feel it sounds completely like me. This is natural since it is a voice repair service but it is still quite strange to listen to.

I really enjoy using the emojis on the Smart Box to have a bit of fun with the grandchildren. I also know you can record and save frequently used phrases and questions so make use easier and quicker during things like medical appointments. Although I've not practiced using it much yet.

I would definitely recommend using the PSPA Voice Banking Funding but I would advise to look into as quickly as possible after your diagnosis, as you will never know when your voice will become affected."



### COLIN SHEARSMITH

"I heard about the PSPA Voice Banking Funding from my SLT. I had been referred to the SLT to take a six-week speech strengthening course and to get regular checks for my swallowing.

Applying for the funding was really easy. My SLT made the referral to PSPA via their Helpline. PSPA quickly approved the funding and then my SLT visited me at home to help install the voice recording app onto my iPad.

Recording my voice was fairly easy too. It took around an afternoon to record the number of

sentences I needed to. SpeakUnique then got in touch around a week later to say the voice repair had been conducted and my voice was now available via the app to use.

When I first listened to the recording of my voice, it was a little strange. But I soon got used to it.

Due to the apathy linked to my PSP, motivation to use the app is quite low but my SLT said it is important for me to practice using the app, whilst I can still speak. I now try and practice using the app two mornings a week.

I've saved some frequently used phrases for ease of use. These include things like 'I need the loo', 'Can we have lunch', and 'Is Chris (my son) coming around?'

Banking my voice and using the app is really straight forward. I particularly like the predictive text feature, so I don't always have to type out the whole sentence.

I would definitely recommend applying for the funding from PSPA. It is quick and easy to access, and you have access to your recorded voice in no time at all."

### APPLY FOR PSPA VOICE BANKING FUNDING

If you are considering banking your voice and would like to talk through how to apply for PSPA funding, please contact our Helpline on **0300 0110 122** or email **helpline@pspassociation.org.uk**

# SUPPORT GROUP UPDATE

In 2020 when we moved our regional Support Groups online we were concerned people would not adjust well to this new way of meeting, but how wrong we were.

Moving our meetings to online gave PSPA the opportunity to open up our support network and set up new Support Groups for specific members of our community, including people living with CBD, those recently diagnosed and carers of all ages. Now that our regional Support Groups are back offering a combination of online and face to face meetings just like old times.

Now we have so many different ‘Support Groups’ it can be a little confusing to understand what each one offers so we thought we would give you a short introduction to each group to help you find the one(s) you need.



## REGIONAL SUPPORT GROUPS

These groups meet in your regions across the UK. The majority meet once a month and offer either face to face or online meetings.

Regional groups provide a warm welcome and friendship for people living with PSP, CBD and their families. It’s also great space to share experiences and gain support.



## NEWLY DIAGNOSED GROUP

Our regional support groups offer amazing support to everyone affected by PSP & CBD however, these meetings regularly host people at different stages of the disease progression and for some people with a new diagnosis this can be quite daunting. So, we set up our Newly Diagnosed Support Group.

These meetings are offered in six-month blocks and each month a different health professional attends to talk about their role and the management of PSP & CBD. There is also time to ask any questions you may have. There are opportunities to form friendships and share experiences with those at a similar stage to you.

To attend the group, you need to have received a diagnosis of PSP or CBD within the last six months of a new block of meetings starting. The group is open to the person living with the condition and their carer although the focus will be on the person with the condition. The next six-month block starts in January 2023 so if you have recently been diagnosed and would like to attend, please contact the PSPA Helpline on **0300 0110 122** or email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)



### CBD SUPPORT GROUP

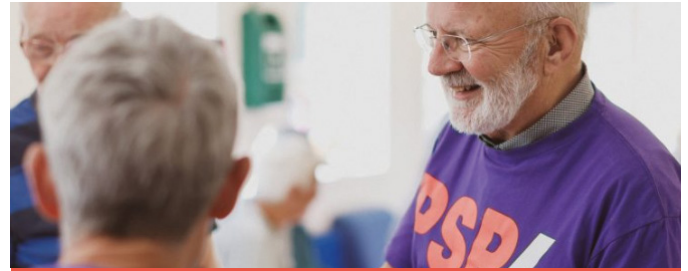
We understand it is so important for people diagnosed with CBD to have their own space to share experiences and information to support them to live the best life possible with the condition.

The first CBD Support Group took place online in March 2021 and since then we have seen interest in the group grow to 83 people.

The group meet monthly online, and every other month they are joined by a health professional to answer any questions people may have about living with a diagnosis of CBD.

This group is specifically for people with a diagnosis of CBD. We realise that people may need support from their carer to attend the meeting and that is fine however the focus of the meeting is on those with the condition.

If you are living with a diagnosis of CBD and would like to join the group, please contact the PSPA Helpline on **03000 0110 122** or email **helpline@pspassociation.org.uk**



### CARERS SUPPORT GROUP

If you are caring for someone living with a diagnosis of PSP or CBD this is the group for you.

These regional groups offer a relaxed and friendly environment for carers to get together once a month online.

A different topic is offered for discussion each month including:

**October** – Carers and PSP & CBD Research

**November** – Physical Health for Carers including 30 minute session on stretching and relaxation

**December** – Activities for Christmas

We offer evening meetings from 7pm to 9pm and one daytime meeting from 11am to 1pm. For meeting dates in your region, please contact our volunteering team on **01327 356137** or email **volunteering@pspassociation.org.uk** to receive an invite.

### PSPA YOUTH SUPPORT GROUP

We know there are many young people out there who are caring for someone with PSP or CBD. There are also many of them who are supporting not only their parent with PSP or CBD but also their other parent who is the main carer.

Having a space to chat with someone of a similar age and talk through juggling studying, finding a job etc. whilst offering support is so important. This is where our Youth Support Group comes to the rescue.

The group meets regularly via Zoom, has its own Facebook page and WhatsApp group so there are many ways to find support any day, any time.

The group is open to anyone up to the age of 30 years old, so if this sounds like something that interests please go to page 7 to read all about the group and our lovely volunteer Kathryn who facilitates the meetings.

# CREATING A LASTING LEGACY

Legacy income, which is a donation you can make through your Will, is the cornerstone of funding at PSPA, generating approximately 25% of income, annually.

A gift in your Will is a great way of giving. It allows you to do something amazing in memory of a loved one or in your own name. It also doesn't affect your spending in your lifetime, and allows you to think of your family's need first.

From a practical point of view, a gift to charity is free from inheritance tax and if you leave more than 10% of your entire estate to charity then the total amount of inheritance tax you pay reduces from 40% to 36%.

To assist PSPA supporters in obtaining or updating their Will, we have partnered with Farewill to trial a free Will scheme. This is exactly what it says; if you need a Will you can use this service free of charge.

By having a Will, you can give peace of mind to loved ones, and by considering a gift in your Will you offer the potential of having a huge and lasting impact for PSPA, helping us develop our support services and continue to fund vital research, now and in the future.

Farewill is the largest Will writer in the UK and very well recognised for their quality of customer care and attention to detail. By taking part in this trial you are under no obligation to leave a gift in your Will to PSPA, but we would be delighted if you would consider it.

If you would like to about our free Will scheme and how it will help PSPA, email [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk), otherwise, you can go direct to Farewill by calling them ib **0208 050 2686** or visit [farewill.com/pspa-autumn22](http://farewill.com/pspa-autumn22)

## LEGACY FAQs

### What is a Legacy?

A charitable legacy is a gift that someone leaves to a charitable organisation in their Will.

### Why is legacy giving important?

Legacy giving ensures donors will be remembered for their generosity and commitment to your nonprofit's purpose long after their passing.

### What information do I need to leave a gift in my will to PSPA?

To leave a gift you can use our free Will scheme, talk to a local solicitor, or professional Will writer. They will ask you for the charity name, the charity address, and the charity number.

## PSPA

Margaret Powell House  
415a Midsummer Boulevard Milton Keynes  
MK9 3BN  
T 01327 322410  
Registered charity number England and Wales  
1037087 and Scotland SCO41199.

### What type of gift makes the most difference?

Any gift to PSPA in your Will can make a big difference. Many supporters choose to leave a small percentage of their estate, as this type of gift doesn't lose value over time. This is called a Residuary gift. Otherwise, you can leave a set sum of money, or items.

### Do I need to specify how my gift should be used?

Your gift will make an incredible difference however it is spent, so we encourage supporters not to specify how their gift might be used, however if this is something you would like to discuss please contact Helen Holman, Head of Fundraising, at [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)





# LEAVING A GIFT IS AN EASY WAY TO SUPPORT PSPA

After Jeanette Quinn's mum was diagnosed with PSP in 2006 the family were surprised how few healthcare professionals were aware of the condition.

"My mum was still a vivacious, young at heart woman when she passed away at 76-years-old.

I have two sisters, and the four of us were extremely close. Mum called us 'her girls' and my younger sister and I spoke to her on the phone three or four times a day.

When mum began to fall, we thought it was a result of the double hip replacement she'd had and that they had finally worn out. But as time went on a few elements of her personality changed too. After GP investigations went around in circles, I took mum to the specialist hospital for her neurology appointment, so I was there when she received the news. Mum was a little confused, but I heard what the doctor said, and knew what it meant.

The doctor felt he had to repeat it for mum. 'You understand what this means? There is no recovery for this.' It was definitely a shock, but it was something I needed to hear.

None of our family had heard of PSP before mum's diagnosis. Mum lived in Wales with her second husband Eric, and at the time she was ill I was living in Warrington, so I wasn't too far away. I tried to see her as much as I could and continued to ring her regularly too.

That was one of the saddest things, when the PSP progressed, that our phone calls began to get less and less. I could hear mum struggling to get her words out. But despite her losing her voice, and seeing her deteriorate, she still kept that same big, beautiful smile until the end.

Our Mum reached the end of her journey in 2012. The hospital team were fantastic and let me stay with Mum for the 19 days she was cared for by them. We could see in her eyes, she didn't want to leave her girls. It was heart breaking.

Throughout this time, I felt really helpless. Once we had lost mum, I wanted to host an event of some kind, to raise awareness and funds for PSPA too, to feel like I was doing something to help. But there was so much to do still. And that's when I thought about my Will. I needed to update it anyway, once my sister Dolores (who has a learning disability) started living with me, and so that's when I made the decision.

During mum's journey, it really hit hard, that very few healthcare professionals had heard of PSP. So, leaving a gift in my Will, well it was an easy way to help with that problem. To help raise awareness, ensure support of people living with the condition continues, and aid research, all in mum's name. Even though mum is gone now, she still gives us a lot of joy, as we relive so many wonderful memories. I know my mum would have supported my decision to leave PSPA a gift in my Will and aid awareness raising. It's her legacy, as is the continuation of phone calls with each other. Her girls still chatting away with each other every day."



# HELP CALL FOR IMPROVED NEURO SERVICES: BACK THE 1 IN 6

PSPA is supporting The Neurological Alliance’s #BackThe1in6 campaign.

We’re calling on governments across the UK to prioritise services for the 1 in 6 people living with a neurological condition and establish a Neuro Taskforce.

You can help by signing the #BackThe1in6 petition.

Last year, we asked you and thousands of people across the UK with neurological conditions to take part in My Neuro Survey.

Over 8,500 people shared their experiences in the UK-wide survey, including many (over 30) people living with PSP & CBD.

Now the results are in. 1 in 6 people in the UK live with a neurological condition, but it’s clear there simply isn’t the staffing or services in place to support them.

## JOIN US: BACK THE 1 IN 6

Join us in calling on governments across the UK to #BackThe1in6 and set up a Neuro Taskforce to deliver real change.

Survey respondents reported that:

- Delays to treatment and care can change your life. 55% of adults and 60% of children and young people living with a neurological condition experienced delays to routine appointments with specialists in the last year
- Most people with a neurological condition are unable to access the mental wellbeing support they need. 40% reported their mental wellbeing needs are not being met at all
- Finding out you have a neurological condition is scary and confusing. Receiving the right information and support can make a real difference. 2 in 10 were not given an explanation of their diagnosis. Almost 4 in 10 adults reported not being given any information at all.

**This must change.**

As a member of the Neurological Alliance, we’re calling for a Neuro Taskforce to be established by governments across the UK.

We want the Neuro Taskforce to create a plan for a radical transformation of services for people with neurological conditions, including PSP & CBD, and provide healthcare professionals with the support needed to deliver this.

We want to make sure that the next My Neuro Survey results find a vastly improved picture of high quality neuro health and care services.

You can help by signing the #BackThe1in6 petition. Sign the petition now and share with everyone you know, in real life, by email and on social media: [tinyurl.com/BackThe1in6](https://tinyurl.com/BackThe1in6)

Thank you.





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## RESEARCH LOOKING FOR EARLY BIOMARKERS TO AID DIAGNOSIS OF PSP & CBD

Professor Michele Hu at Oxford University NHS Trust is leading several studies aiming to identify early biomarkers of Parkinson's, PSP & CBD to aid early diagnosis and access to care, whilst also supporting the PROSPECT study. Here Professor Hu shares an update on these projects and how you can get involved.

"My interest in Atypical conditions such as PSP, CBD and MSA, began during my medical training. Seeing patients face ongoing challenges, not just with obtaining a diagnosis and the progression of symptoms but also accessing timely, relevant and joined-up care, really motivated the direction of my career.

I've been a consultant for 17 years and ten years ago I set up a multidisciplinary clinic for people diagnosed with Parkinson's, PSP, CBD and MSA living in Oxfordshire and surrounding counties. We currently have around 150 people living with PSP, CBD and MSA attending this clinic.



I am also an academic, researching early biomarkers for Parkinson’s and Atypical conditions, largely across the Thames Valley area. This is a really exciting area of research, with cross disciplinary working through which we have learned so much more about the causes and progression of PSP & CBD symptoms than ever before. I feel really lucky to be able to combine my clinical work with research, and I feel my experience as a clinician is extremely beneficial as I understand the relevant milestones of the conditions. In turn, this then helps me to identify what will really help and work diagnosis wise.

My research interest mainly lies within psychiatric and cognition aspects of these conditions. I’m particularly interested in experiences of hallucinations, psychosis, and memory problems, as well as how sleep affects neurodegeneration. I focus not just on the patient but the impact on the whole family.

As part of this research, I am leading a longitudinal study looking at biomarkers for early and prodromal Parkinson’s disease, with a focus on REM sleep behaviour disorder and how sleep affects neurodegeneration. We have 1,600 participants, including 1,000 Parkinson’s patients, 300 control subjects and 300 people with REM sleep behaviour disorder. To track progression, we are collecting data using:

- Spinal fluid, plasma, serum and skin samples
- Brain imaging such as DaT and MRI scans
- Smart-phone based tests for speech, reaction time, tremor and walking gait
- Sleep EEG/EMG markers.

So far, findings show promising results in determining if an individual might develop symptoms such as a tremor or balance issues, within 18 months. The impact these findings are really useful for improving quality of life for patients, as referrals to physio, occupational therapy or falls



clinics can be made to support the specific needs of the patient and potentially reducing emergency hospital admissions. Research wise, it would also support early recruitment to clinical trials.

Through the results of the Parkinson's study, it was clear the smartphone test could also provide a digital test aiding early diagnosis of PSP, CBD and MSA.

We have started to recruit Atypical patients to a separate study looking at how they perform the smartphone test in clinic or at home. So far, we have 42 people taking part, and are actively recruiting more. At the moment, the Atypical section of the study is too early, with too small a group, to give any useable findings but we are hopeful we will grow participation throughout this year.

Participation in this study does require initial attendance at clinics at the John Radcliffe Hospital in Oxford, however patients are able to take the smart phones home so they can conduct that portion of the study themselves.

Oxford atypical patients can also consider taking part in the UK-wide PROSPECT study, which similarly is tracking progression of symptoms in atypical cohorts.

In addition to these studies, at Oxford we are also beginning to audit access to NHS care to aid clinical management. So far, we have 300 people recruited, who we have been asking questions such as if they had access to speech and language therapy and physiotherapy, if they had a PEG fitted and if they received input from a palliative care team.

Hopefully, if we gain PSPA funding, we aim to extend our work to provide research work experience for students. This would involve detailed interviews with patients and family members. If successful we aim to start this study in the autumn."

### GET INVOLVED IN RESEARCH

If you would like to become a participant of Professor Hu's research studies, you can get in touch with the team at:

#### ATYPICAL STUDY

Parkinsons.discovery@nhs.uk

#### PROSPECT

Prospect.discovery@nhs.net.uk

### FURTHER READING

#### If you would like to read more about Professor Hu's research, please visit

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Lo C\*, Arora S, Baig F, Lawton MA, El Mouden C, Barber TR, Ruffmann C, Klein JC, Brown P, Ben-Shlomo Y, de Vos M, Hu MT. Predicting motor, cognitive and functional impairment in Parkinson's. *Annals Clin Trans Neurol* 2019;6(8):1498-1509; <http://dx.doi.org/10.1002/acn3.50853>

# THANK YOU TO OUR PRIM VOLUNTEERS!

The first meeting of our new public involvement group took place virtually in July 2022. Five PSPA Research Involvement Members (PRIM) joined Annalisa Casarin, PSPA Research Coordinator, in a discussion about how PSPA could be the 'critical friend' for companies and researchers.

PRIM has been formed to ensure engagement and involvement of people living with the conditions, carers and family members in research funded and supported by PSPA.

The aims of the group are to:

- Ensure that the charity maximises its research performance on behalf of people affected by PSP & CBD
- Increase the use of involvement and co-production to support research activities
- Provide people living with the conditions and carers a voice regarding priorities in research into the conditions
- Assist, support and advise researchers and act as a 'critical friend' on how best we can improve research strategy and projects.

In return, PSPA provides training and support, keeps members updated on research activities and outputs, provides feedback from researchers and companies the group impact, and share study results.

When a member of the public provides insights on a research proposal, it is more likely that proposal will receive better review from a funding panel and quicker ethical approval. This because people with experience of the condition, as a patient or a carer, will provide feedback as a research participant and this helps researchers to tweak study processes.

Involvement of the public in research improves the relevance, clarity and feasibility of research design and tools with benefit from both sides, researchers and participants.

Meetings run every month virtually, but members are actively involved during the period between calls in reviewing research materials and providing



insights on research strategy, scientific days agenda, and content of our website. The aim of the partnership between researchers and PSPA is to identify unmet needs and novel research areas, and to communicate research in a way that is understandable by lay members, bringing research findings to the people affected by PSP & CBD, our supporters and funding partners.

## PRIM VOLUNTEERS IN ACTION

This summer two of our PRIM volunteers, Janet and Roger, met with the pharma company Amylyx to run through research phases and potential effects of the new drug the company is developing.

Janet and Roger enjoyed their first engagement as part of the PSPA research involvement members.



Janet said “It was really enjoyable working with the team from Amylyx. I was really impressed with how committed they were to think about people with PSP & CBD and how to improve their lives. I’d also like to express how valuable it was to be able to refer to the experience of those who I’ve got to know through the PSP & CBD community on Health Unlocked. I hope we did them justice!”

Roger added “I greatly appreciated being able to provide some input into the thought processes Amylyx are going through in developing the new drug. It gave tremendous encouragement to see the care and empathy the company is showing in many aspects of the development. What also became clear as we discussed matters was how much the regulatory and other formal processes bear directly on the development of the drug as it proceeds through many testing and clinical stages. “It was for me a privilege to be able to offer practical guidance on behalf of people living with PSP & CBD as to the practicalities of testing that Amylyx are getting nearer to undertaking. As far as I was

concerned it was a new and different experience to act as a volunteer in this way. So many people among those touched by the scourge of PSP & CBD are volunteers and this role was a welcome and different one for me. This activity adds to the tangible hope we all share with staff, researchers, trustees and volunteers for a treatment of PSP & CBD one day in the future.”

#### **GET INVOLVED IN PRIM**

If you would like to join the PRIM, please express your interest sending an email to [volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk)

You don’t need to have previous experience with research, just the enthusiasm to join a fantastic group of people who are willing to dedicate some of their time to improve research quality and get one step closer to finding a cure for the conditions.



**“SEEING MY BAUBLE ON  
PSPA’S CHRISTMAS TREE  
MEANS A LOT TO ME”**

We understand Christmas can be a difficult time for many of the people we support. It is a time for family, for traditions and celebration. But for families who have recently lost a loved one to PSP or CBD, it can be a difficult time of year to navigate.





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## “DONATING TO PSPA’S BAUBLE APPEAL HELPS KEEP MUM’S MEMORY ALIVE AND GIVES BACK TO THE CHARITY WHO SUPPORTED US.”

Our annual Bauble Appeal helps families to donate to PSPA’s vital support services and fund life-changing research, in memory of their loved ones. It also enables you all, to keep up family traditions, in keeping your loved one close to your heart during this festive time of year.

Aileen began supporting the Bauble Appeal in 2019 after her mum passed away from PSP in early December 2017.

“Christmas has always been a big family affair. Everyone descends on my house, but mum was always the centre of our celebrations. She loved being surrounded by her children, grandchildren and great grandchildren.

Mum passed away from PSP in early December 2017 and the first year’s festivities were difficult as it was hard having Christmas celebrations without her. Donating to PSPA’s Bauble Appeal is a fitting tribute to Mum at Christmas.

Mum had been poorly for a while before her diagnosis. In hindsight, there were lots of little, gradual signs something wasn’t quite right. At the time, we put it down to her getting older but when the falls began, we sought help.

We’d never heard of PSP before, but we were lucky the neurologist signposted us onto PSPA and we reached out straight away.

PSPA were not only a listening ear, they also made sure healthcare professionals involved in mum’s care had plenty of information and were educated about PSP too. This meant they could provide mum with the best support possible, even as her symptoms progressed.

Even though mum is no longer with us, she remains central to our Christmas plans. I still use all her Christmas recipes and donating to PSPA’s Bauble Appeal feels like the right thing to do too. It helps keep mum’s memory alive and helps the charity who supported us following mum’s diagnosis.

Seeing the photo of the PSPA Christmas tree, with my bauble, dedicated to mum included on the branches, means a lot to me. It is definitely a tradition I will keep going for mum.”

### **DEDICATE A BAUBLE IN MEMORY OF SOMEONE YOU LOVE WHILST HELPING PSPA**

You too could donate to PSPA in honour of someone affected by PSP or CBD.

You can visit [pspassociation.org.uk/christmas](https://pspassociation.org.uk/christmas) where you can donate and create an e-card to show someone you love you are thinking of them.

Alternatively, email [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk) to receive a Bauble Appeal pack.



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## DAD CAN'T SPEAK ANYMORE BUT HIS LAUGH KEEPS US ALL SMILING

Tracy Rackley's dad was diagnosed with PSP seven years ago. Here Tracy shares details of her dad's progressing symptoms and how she is treasuring every moment with him.

"As a physiotherapist I was aware of PSP and had directly worked with a handful of patients who are living with this very cruel disease. Despite this basic knowledge, nothing could have prepared me when my father was diagnosed.

Dad was 68 years old when my mum and I started to notice that something wasn't quite right.

Six months into retirement dad started falling. Unexplained, random falls. We laughed it off, as did he. At that point he was able to get up himself without too much fuss. No injuries just bruised pride.

More and more falls followed, as did a visit to the GP and a referral to MSK outpatients to investigate. Dad was given exercises to strengthen his lower limbs having been told he was just losing power as he was 'getting older'.

In those 12 months after his retirement we watched him deteriorate to the point where he needed a walking stick to get around. He was also starting to struggle maintaining eye contact with us. His concentration seemed to be limited. Dad always loved a laugh but now he would often laugh inappropriately and this laughter would end with him in tears. Then



came the speech problems. Word finding, volume, growling with frustration when he couldn't find the words he wanted to use.

We got another referral to medicine for older people but was sent away with more physio appointments.

I know my dad and know that what we were witnessing was not the normal process of ageing. I was convinced he had some kind of neurological deficit and both mum and I pushed for a referral to neurology.

By this point I was thinking it was Parkinson's disease. A visit to the neuro consultant confirmed this and dad was started taking one of the anti-Parkinson's drugs. But they made his symptoms worse.

On his 70th birthday we returned to the neuro consultant to be told, based on his deterioration, this was not Parkinson's; indeed, it was PSP and there was no treatment.

Determined to keep dad at home, mum became his full-time carer and I reduced my working hours so she could have a break when I was there.

We moved mum and dad closer so my husband and I could be around to help, and that has been a massive comfort to both me and my parents. They are now only one minute away and I see them most days.

Earlier this year we took the decision to put carers in place. Mum couldn't carry on as she was as dad needs 24hour monitoring as his anxiety levels rocket if he can't see one of us. He will try to get up himself to find us then ends up on the floor. This means he has mum up two or three times in the night ringing his bell (I bought it for him as he can't shout for help), checking she's there and he's not alone.

As dad's symptoms have progressed, we can no longer hold a conversation with him. This is a real shame as I used to love putting the world to rights with dad and doing quizzes with him. Dad tries so hard to communicate but it's single word answers only now. The sad thing is his cognition is absolutely spot on. He knows everything that goes on and his memory is second to none, he just can't speak.... or walk... or do anything for himself anymore.

A speech and language therapist is closely monitoring dad's swallow because he is now struggling to eat safely. He coughs and splutters as the food sometimes goes down the wrong way. He will soon be fitted with

a PEG and be fed through a tube in his stomach. We know this will be a difficult transition for dad as eating is his favourite pastime.

Dad's amazing sense of humour and ability to laugh at himself has been turbo charged by his PSP. So, despite the challenges we spend a lot of time laughing and laughing... with him, not at him. His smile and cheeky laugh are so infectious and everyone who comes into contact with him loves this.

It was dad's 75th birthday in early July. He asked for a party.... dad doesn't usually do parties. But a BBQ is what he wanted so it's what he got. Family and friends came from far and wide to share his day. He couldn't really speak to anyone but he had a few beers and the smile on his face said it all. We think this request was his last goodbye. He's a smart and intelligent man locked in a body that won't do what he wants, and he knows it's failing him.

I don't know how long I have my beautiful dad for and where this illness will take him next. I can only surmise and assume it's not going to be pleasant but I will treasure every single moment I have with him and give him everything I can until the day he leaves us.

If you are caring for someone with PSP, treasure every single moment you have with them. Ask for help if you need it and don't leave it too late before you do. There is no shame in asking. If your person goes in hospital be sure to explain the complexity of this condition and push to be present as much as you can, especially at meal times as the nursing staff don't always understand the condition.

Tell people that when your person is staring and fixating it's nothing personal, it's the PSP that fixes their gaze.

Tell people that if your person is laughing or crying it's nothing personal, it's their PSP.

Tell people that if your person is making strange growling noises it's nothing personal, it's their PSP.

But most of all, tell people that if your person looks as if they don't know what's going on, it's their PSP. And in actual fact, they know every single thing that's being said and done, they just can't express they know."

# RECRUITING PARTICIPANTS FOR A NEW STUDY INTO PSP

Following the promising results from their LRRK2 genetic variant research, Dr Ed Jabbari and Professor Huw Morris are now recruiting participants for a follow up study.

PSP is an incurable neurodegenerative disease caused by the brain build-up of altered protein called tau, leading to progressive impairments in balance, eye movements, speech/swallowing and cognition. We all have tau protein in our brain, but in PSP and related disorders, tau protein is altered making it more sticky and likely to clump together inside brain cells. It was hoped that targeting the malfunctioning tau protein would be able to slow down the progression of PSP but unfortunately this has not proven to be the case in clinical trials.

Through PSPA funding, a study led by myself and Professor Huw Morris discovered that common genetic variation (the variation in the DNA sequence in our set of genes) near a gene called LRRK2 is associated with the rate of disease progression in PSP. Additionally, recent work has supported this novel discovery by showing that LRRK2 plays a key role in the spread of tau protein in the brain. Interestingly, there is a well-established link between the LRRK2 gene and Parkinson's disease. LRRK2 is an enzyme (a protein that starts a chemical reaction) whose excess activity leads to downstream effects on a number of biological processes, including lysosomal dysfunction (lysosomes are cells components involved with various cell processes), which has been shown to be important in the development of Parkinson's. As such, there are ongoing clinical trials of LRRK2-targeting drugs in Parkinson's patients.

I am very happy to announce that I have recently acquired a Venture Grant from CurePSP to work on a follow up study of LRRK2. In this study, I will recruit 40 PSP patients and 40 healthy controls. To take part in the study, patients need to have a clinical diagnosis of PSP, be able to mobilise independently or with a mobility aid, and not be taking any blood thinning medications.

The study will be the first to use cutting-edge tests to measure total LRRK2 protein levels and LRRK2 kinase

activity in blood samples from PSP patients. This data will be used to assess whether these measures are increased in PSP (relative to healthy controls), and whether they are associated with the trajectory of clinical disease progression. Additionally, we will assess the relationship between blood LRRK2 markers as well as related markers in urine and cerebrospinal fluid. If we show that LRRK2 markers are increased in PSP and/or related to disease trajectory, then this may provide further evidence for setting up clinical trials of LRRK2-targeting drugs in PSP patients.

If you were part of PROSPECT-M-UK, you can still take part to this new study.

Please contact me at [e.jabbari@ucl.ac.uk](mailto:e.jabbari@ucl.ac.uk) if you are potentially interested in taking part in the study.

Or if you would like more information, contact the PSPA research coordinator or use the address [research@pspassociation.org.uk](mailto:research@pspassociation.org.uk)





# A VIRTUAL GOLDEN TRIANGLE CHALLENGE FOR MUM

This spring Eram Osman challenged herself to completing a virtual challenge in memory of her mum, who would have turned 80 on 2 May.



“My mum lived with PSP for a very long time, and sadly, she left us in October 2016. Since then, I have been doing what I can to raise awareness and funds for PSPA.

On 2 May 2022 my mum would have celebrated her 80th birthday. I wanted to do something to keep her memory alive. It was important for me to have some relevance to ‘80’ and to India where my mum was born and spent most of her childhood and teenage years. So, I decided to take on the Golden Triangle virtual challenge, which covers 476 miles. I set myself a goal to complete this distance in 80 days! This worked out at running six miles per day starting on 2 May.

My friend recommended the Conqueror app. Your journey is tracked virtually, and you can see where you are on the map. You get beautiful postcards, and for every milestone you hit, a tree is planted somewhere in the world on your behalf, or plastic is removed from the ocean.

Monday 2 May arrived; it was literally the day my holy month of Ramadan ended. I had been keeping my

fasts, so I wasn’t fuelled up as I should have been, but the date/timeframe was really important to me.

The first couple of weeks were really tough. On day 15, I hit 100 miles which was 20% of my distance, it felt good, and it was so exciting to hear that a tree was planted in the world somewhere on my behalf. The weather was getting better, I was in a good routine, making sure I stretched and kept mobile throughout the day.

The support I was receiving from my family, friends, colleagues and PSPA family kept me going. On day 29, I hit 200 miles; I was nearly at the halfway mark. But, on day 40 I had a bit of a setback, I got a shin splint in my right leg. It was so painful, I could not even touch it, let alone walk properly.

I was really upset and had to figure out what I was going to do, I had 40 days and 205 miles to go.

For the next 13 days, I just managed slow walks, I was not achieving my daily distance, I just did the best I could. The turning point came on day 53, it was more of a relief than anything else. My leg felt much stronger, and I started to do six-mile brisk walks.

On day 66 I had covered 90% of the distance and I only had 47 miles to do in 14 days. By now I had really started to enjoy the challenge again. The days just flew by and to my surprise I completed the challenge on Sunday 17 July on day 77.”

Read some of Eram’s challenge updates on her fundraising page at [donate.giveasyoulive.com/fundraising/eram-osman](https://donate.giveasyoulive.com/fundraising/eram-osman) or search for #India80Challenge on Twitter.

If anyone is interested in doing a Conqueror challenge and would like 10% off, take a look here [www.theconqueror.events/r/EO527](https://www.theconqueror.events/r/EO527)

# RAISING AWARENESS ACROSS THE UK WITH ED'S LACE

Thank you to everyone who once again embraced our Ed's Lace awareness campaign. Up and down the country, people have been wearing their Ed's Lace with pride at work, whilst training for a challenge and on their handbags. We've also loved seeing all of the fantastic crafts being made using the lace, including head bands, bracelets, bag charms and gift cards!

You can still help raise awareness of PSP & CBD by opening conversations wearing Ed's Lace by purchasing a lace from our website shop: [www.pspassociation.org.uk/fundraising/shop/](http://www.pspassociation.org.uk/fundraising/shop/)

Here are just a few of the photos we have been receiving. If you'd like to share your Ed's Lace photos, please email them to [communications@pspassociation.org.uk](mailto:communications@pspassociation.org.uk)





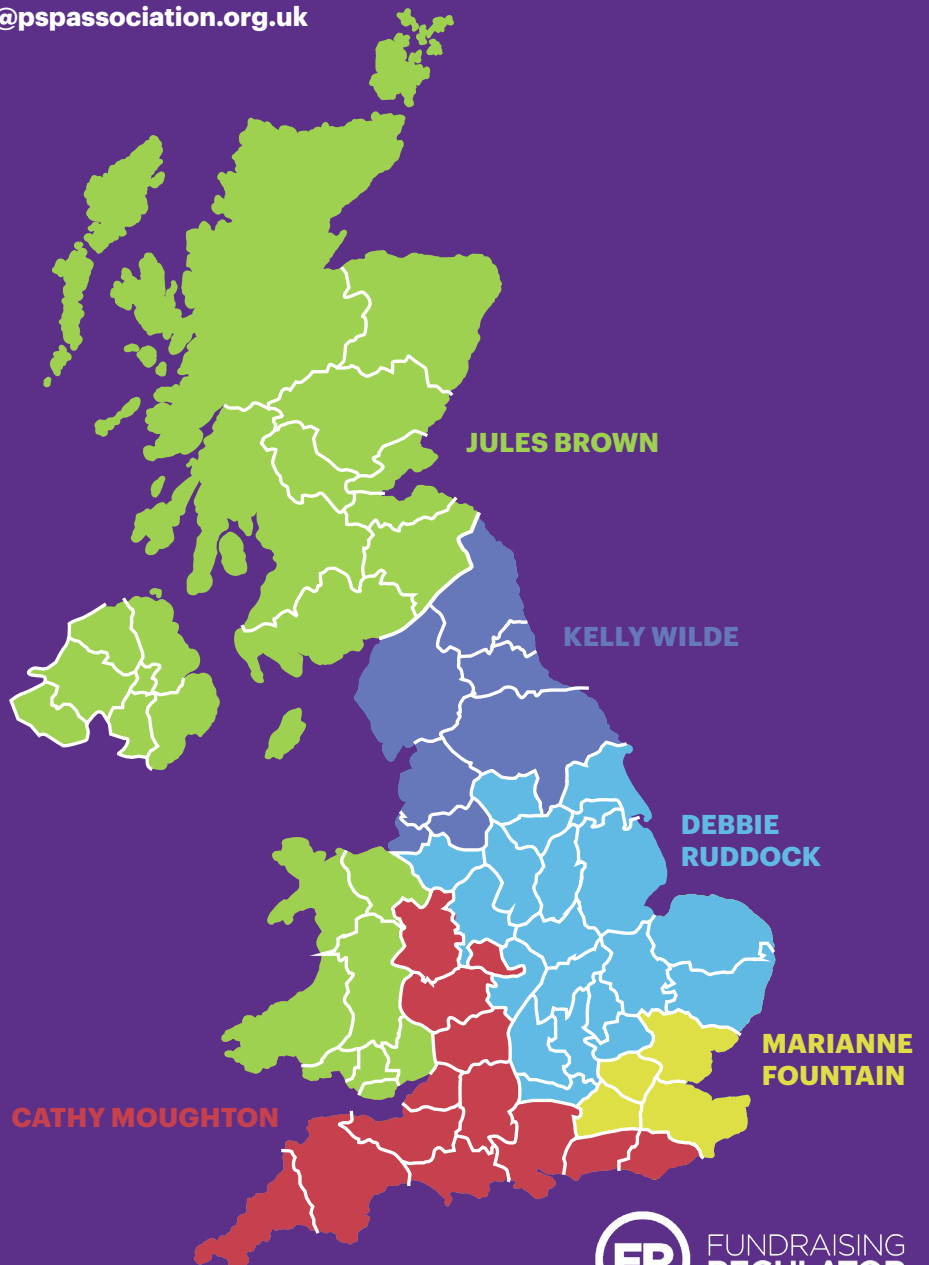
# HERE FOR YOU

Our Helpline Care Navigators are here to support people living with and affected by PSP & CBD. Each Helpline Care Navigator has a designated area (see map) where they can provide proactive support, including:

- Information on all aspects of living with PSP & CBD, such as symptom management, benefits and entitlements and everyday living.
- Emotional and practical support.
- Contact details for local support, which may include Support Groups.
- Information about how PSPA can support you.
- Information about health and social care and how to access these services.
- Signposting to other sources of information.
- Referral for non-means tested benefits applications via Department of Work and Pensions (DWP) home visiting service.
- Supporting evidence about PSP & CBD for Blue Badge applications and Continuing Healthcare applications.
- Provide specific information written for health and social care professionals and access to Education Volunteers.

**Our Helpline and information service is available Monday to Friday 9am-9pm.**

Tel: **0300 0110 122** or email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)



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